The right to health implications of data-driven health research partnerships

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Abstract

The public-private partnership between DeepMind Health and the NHS sparked public outcry for violating patient privacy, capturing the attention of right to privacy scholars and practitioners. By contrast, critiques pertaining to the broader political economy of the collaboration- which invoke debate around public-private partnership models and Big Tech's expansion into healthcare markets- have not been sufficiently investigated by human rights scholars, despite implicating socio-economic rights.

This thesis explores the political economy of the DeepMind-NHS partnership and its implications for the right to health, applying an interdisciplinary lens that synthesises insights from political economy, critical data studies, and international human rights law. Drawing on findings from documentary analysis of grey literature and semi-structured interviews with key stakeholders and opinion-leaders, it argues that data-driven health research partnerships like DeepMind-NHS generate resource asymmetries by enabling technology companies to extract wealth from publicly-funded data in exchange for inequitable and uncertain public benefits. These partnerships thus fail to leverage public sector data resources to realise the right to health, highlighting the need for alternative models. The thesis further reveals knowledge asymmetries that prevent effective state and corporate accountability for the right to health, exposing the limitations of existing instruments for corporate human rights responsibilities and exploring the rationale for additional human rights obligations for Big Tech.

Together, these findings reveal that data-driven health research partnerships risk infringing upon the right to health, thus challenging the underlying political rationale for public-private partnership and revealing the problematic ethico-legal consequences of Big Tech's commercialisation of health data.

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Abbreviations

AAAS- American Association for the Advancement of Science

AAAQ- availability, accessibility, cultural acceptability and quality

AI- Artificial Intelligence

AKI- acute kidney injury

BHR- business and human rights

CCPR- UN Committee on Civil and Political Rights

CDS- critical data studies

CESCR- UN Committee on Economic, Social and Cultural Rights

CT- computerised tomography

CSR- corporate social responsibility

ECHR- European Court of Human Rights

EHRC- Equality and Human Rights Commission

ESC- economic, social and cultural

ESCR- economic, social and cultural rights

EPR- electronic patient record

FOI- Freedom of Information

GDP- Gross Domestic Product

GHP- global health partnership

HRIA- human rights impact assessment

ICCPR- UN International Covenant on Civil and Political Rights

ICESCR- UN International Covenant on Economic, Social and Cultural Rights

ICO- Information Commissioner's Office

IGW- Intergovernmental Working Group

IP- intellectual property

ISA- information sharing agreement

IT- information technology

JCHR- Joint Committee on Human Rights

MAR- maximum available resources

MNC- multinational corporation

MOU- memorandum of understanding

MRC- Medical Research Council

MRI- magnetic resonance imaging

NGO- non-governmental organisation

NHS- national health service

NHRI- national human rights institute

NIH- National Institute of Health

NPM- New Public Management

PFI- private finance initiative

PIA- privacy impact assessment

PPP- public-private partnership

R&D- research and development

UDHR- Universal Declaration of Human Rights

UN- United Nations

VC- venture capital

VfM- value for money

WHO- World Health Organisation

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Chapter 1: Introduction

1.1 The case study: the DeepMind-NHS partnership

1.1.1. The DeepMind-Royal Free data transfer

DeepMind is a UK-based artificial intelligence (AI) company that was acquired by the Google conglomerate in 2014.[1] In July 2015, physicians in the Royal Free London NHS Foundation Trust- one of the largest healthcare providers in the United Kingdom's national health service (NHS)- approached DeepMind about the possibility of developing new clinical software.[2]

In September 2015, the Royal Free signed an Information Sharing Agreement (ISA) with the company to transfer approximately 1.6 million identifiable patient records into third-party servers to be processed by Google;[3] these records included

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[1] The relationship between Alphabet Inc, Google and DeepMind is complex and has evolved over time. In 2015- after DeepMind's acquisition by Google- Google was restructured and all companies within the Google conglomerate- including DeepMind- were subsumed under holding company Alphabet Inc. In 2018, DeepMind Health- the unit of DeepMind focused specifically on health and involved in the company's collaboration with the NHS- merged with Google Health, one of the subsidiary companies of Alphabet Inc. For this reason, I refer to DeepMind Health, DeepMind, Google Health, Google and Alphabet Inc at different times throughout this thesis depending on the context of the discussion and the company's organisational structure at the time. However, for clarity and consistency, I refer to the collaboration between the company and the NHS as DeepMind-NHS throughout the entirety of the thesis; Samuel Gibbs 'Google buys UK artificial intelligence startup Deepmind for £400m' (*The Guardian*, 27th January 2014) <www.theguardian.com/technology/2014/jan/27/google-acquires-uk-artificial-intelligence-startup-deepmind> accessed 4 August 202

[2] Julia Powles & Hal Hodson 'Google Deepmind And Healthcare In An Age Of Algorithms' (2017) 7 Health Technol <https://link.springer.com/content/pdf/10.1007/s12553-017-0179-1.pdf> accessed 4 August 2020.

[3] Royal Free London NHS Foundation Trust 'Information Sharing Agreement' (29 September 2015) (document is no longer available online- pdf available from author); Powles & Hodson (n2).

information on patients who had undergone pathology tests at the Trust within the past five years as well as data from the Trust's radiology and electronic patient record (EPR) systems.[4] The data included highly personal information about patients including HIV status, details of drug overdoses and abortions, as well as routine hospital administration such as the location and status of patients.[5]

DeepMind claimed it intended to use the data to develop a new mobile application called Streams, which provides patient safety alerts for Acute Kidney Injury (AKI); a relatively common condition in UK affecting kidney function.[6] The project was approved by the NHS Research Ethics Committee in October 2015 and the data transfer commenced the following month.[7] These developments occurred behind closed doors, with no immediate announcement from either party.

In January 2016, the two parties signed a Memorandum of Understanding (MOU),[8] which indicated their intentions to establish "a broad ranging, mutually beneficial partnership, engaging in high levels of collaborative activity and maximising the potential to work on genuinely innovative and transformative projects".[9] Soon thereafter, the company officially launched DeepMind Health, a new unit with a remit "to support clinicians by providing the technical expertise needed to build and scale technologies that help them provide the best possible care to their

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[4] Ibid.
[5] Subhajit Basu 'Should The NHS Share Patient Data With Google's Deepmind?' (*Wired*, 11 May 2016) <www.wired.co.uk/article/nhs-deepmind-google-data-sharing> accessed 4 August 2020.
[6] 'DeepMind Health Independent Review Panel Annual Report' (5 July 2017) <https://kstatic.googleusercontent.com/files/7e0b35e4cb6ccb750cba03fb160a69cc4f24456358042b8313b88943c49dfbce46037e9c89fad32fae986bd08a84e90c792656e0208d1276f1db895dcb42386b> accessed 17 August 2020.
[7] For details of the research approval, see NHS Health Research Authority, 'Freedom of Information (FOI) Act request' (4 July 2017) <www.whatdotheyknow.com/request/410881/response/1001252/attach/2/1718%20FOI%20011%20HRA%20response%20and%20documentation.pdf?cookie_passthrough=1> accessed 7 September 2020. See also Powles & Hodson (n2).
[8] Royal Free London NHS Foundation Trust 'Memorandum of Understanding' (28 January 2016) <https://drive.google.com/file/d/0BwQ4esYYFC04anR4VHM3aXZpMTQ/view> accessed 10 August 2020.
[9] ibid para 6.1.

patients".[10] Though this announcement publicised the company's work with the NHS for the first time, it made no mention of the preceding data transfer.

1.1.2. The Privacy Controversy

The partnership first drew attention in April 2016, after *New Scientist* journalist Hal Hodson published an article revealing the true extent of the data transfer between the two parties.[11] The article raised concerns about the privacy implications of the data transfer and the lack of transparency surrounding the deal, arguing that the ISA "goes far beyond what is publicly announced".[12] Hodson's findings catalysed action from the Information Commissioner's Office (ICO)- the UK's data watchdog- who subsequently launched a year-long investigation into the deal in July 2016.[13]

Public controversy was further fuelled in March 2017, when Hodson co-authored with Cambridge academic Julia Powles a widely circulated article criticising the partnership.[14] Privacy and data protection issues were a primary concern for the authors, who highlighted how patients were not notified of the data transfer nor asked to give consent for their records to be used in this way; this lack of consent, they suggested, violated patient privacy and agency.[15] At the heart of the consent debate was DeepMind's justification that it was providing 'direct care'- "a clinical,

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[10] 'We are very excited to announce the launch of DeepMind Health' (*DeepMind blog,* 24 Feb 2014) <https://deepmind.com/blog/announcements/we-are-very-excited-announce-launch-deepmind-health> accessed 4 August 2020, para 3.
[11] Hal Hodson 'Revealed: Google AI Has Access To Huge Haul Of NHS Patient Data' (*New Scientist*, 29 April 2016) <www.newscientist.com/article/2086454-revealed-google-ai-has-access-to-huge-haul-of-nhs-patient-data/> accessed 4 August 2020.
[12] Ibid.
[13] Caroline Donnelly 'ICO probes Google DeepMind patient data-sharing deal with NHS Hospital Trust' (*Computer Weekly*, 12 May 2016) <www.computerweekly.com/news/450296175/ICO-probes-Google-DeepMind-patient-data-sharing-deal-with-NHS-Hospital-Trust> accessed 4 August 2020.
[14] Powles & Hodson (n2).
[15] Ibid.

social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of individuals"-[16] to NHS patients, which would absolve the company from the obligation to obtain patient consent.[17] Powles and Hodson refuted DeepMind's position, arguing that the lack of approval from appropriate regulatory authorities or explicit patient consent amounted to a violation of the Data Protection Act 1998.[18] The authors further suggested that the ISA gave too much discretion to DeepMind in determining how the dataset was processed, blurring the clear distinction between data processor and data controller under data protection law.[19]

In July 2017, the ICO concluded its investigation into the partnership. The Commissioner determined that, although the Royal Free had remained data controller throughout the trial period, the trust had failed to comply with the First, Third, Sixth, and Seventh Data Protection Principles, and had thus violated the Data Protection Act 1998.[20] In particular, she criticised the lack of informed consent and proof of the necessity and proportionality of processing 1.6 million patient records, patients' inability to opt out, and inadequacies in the ISA.[21] The Commissioner requested that the Royal Free establish a 'proper legal basis' for the DeepMind collaboration and future trials, set out how it will comply with the duty of confidence to patients in future deals, complete a privacy impact assessment, and commission

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[16] National Data Guardian 'Information: To Share Or Not To Share? The Information Governance Review' (26 April 2013) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_accv2.pdf> accessed 11 August 2020, 128.
[17] Powles & Hodson (n2)
[18] Basu (n5); Powles & Hodson (n2)
[19] Powles & Hodson (n2)
[20] Elizabeth Denham 'Letter to Sir David Sloman (RFA0627721 – provision of patient data to DeepMind)' (3 July 2017) <https://ico.org.uk/media/action-weve-taken/undertakings/2014353/undertaking-cover-letter-revised-04072017-to-first-person.pdf> accessed 17 August 2020.
[21] Ibid.

an independent audit of the trial of the Streams app;[22] notably, no cautionary fine was issued. In an accompanying blog post, the Commissioner summarised key lessons for other NHS trusts to take from the debacle, concluding that "the price of innovation didn't need to be the erosion of legally ensured fundamental privacy rights".[23]

Soon thereafter, the Royal Free signed up to deliver the Commissioner's recommendations. In an effort to boost transparency around data sharing, the trust created a new section of their website detailing what happens to patient data and providing information about opting out, as well as patient information leaflets and posters addressing commonly asked questions around data sharing.[24] The trust also signed a new and improved contract with DeepMind, which came into effect in November 2016.[25] Finally, they took up the Commissioner's suggestion to commission an independent, third-party audit into the Streams app, which concluded that its use is now lawful and complies with data protection regulation.[26]

DeepMind also responded to the ICO's findings in a blog post, which professed that the company had "underestimated the complexity of the NHS and of the rules around patient data, as well as the potential fears about a well-known tech company working in health".[27] The post outlined the company's efforts to improve

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[22] Information Commissioner's Office 'Royal Free- Google DeepMind trial failed to comply with data protection law' (*ICO blog,* 3 July 2017) <https://ico.org.uk/about-the-ico/news-and-events/news-and-blogs/2017/07/royal-free-google-deepmind-trial-failed-to-comply-with-data-protection-law/#> accessed 17 August 2020.

[23] Elizabeth Denham 'Four Lessons NHS Trusts Can Learn From The Royal Free Case' (*Information Commissioner's Office Blog*, 3 July 2017) <https://iconewsblog.org.uk/2017/07/03/four-lessons-nhs-trusts-can-learn-from-the-royal-free-case/> accessed 17 August 2020.

[24] 'Information Commissioner's Office (ICO) investigation' <www.royalfree.nhs.uk/patients-visitors/how-we-use-patient-information/information-commissioners-office-ico-investigation-into-our-work-with-deepmind/> accessed 17 August 2020.

[25] Ibid.

[26] Linklaters LLP 'Audit of the acute kidney injury detection system known as Streams' (17 May 2018) <http://s3-eu-west-1.amazonaws.com/files.royalfree.nhs.uk/Reporting/Streams_Report.pdf> accessed 17 August 2020.

[27] 'The Information Commissioner, the Royal Free, and what we've learned' (*DeepMind Blog*, 3 July 2017) <https://deepmind.com/blog/announcements/ico-royal-free> accessed 17 August 2020.

transparency, oversight and engagement through the replacement of the original ISA, public announcement of subsequent NHS partnerships and publications of contracts online, the development of a patient and public engagement strategy, and the establishment of the Independent Review Panel.[28]

Since the DeepMind-Royal Free collaboration, Streams has been rolled out to other NHS trusts, including Imperial College Healthcare NHS Trust, Taunton and Somerset NHS Foundation Trust, and Yeovil District Hospital NHS Foundation Trust.[29] Furthermore, the company has established a number of additional research partnerships within the NHS that, unlike the development of the Streams app, seek to develop AI technologies. The first of these- established in 2016- brings together DeepMind and clinicians at Moorfields Eye Hospital NHS Foundation Trust to identify early signs of degenerate eye conditions by applying machine learning to anonymous eye scans.[30] University College London Hospitals NHS Foundation Trust and the company have also partnered in a bid to improve the efficiency and accuracy of segmentation processes by developing AI to identify cancerous tissues on computerised tomography (CT) and magnetic resonance image (MRI) scans of head and neck cancers.[31] Finally, DeepMind established a collaboration with Imperial

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[28] Ibid.
[29] Laura Stevens, 'Google Deepmind and Imperial in streams deal' (*Digital Health*, 22 December 2016) <www.digitalhealth.net/2016/12/google-deepmind-and-imperial-in-streams-deal/> accessed 17 August 2020; 'Enhancing patient safety at Taunton and Somerset NHS Foundation Trust' (*DeepMind Blog*, 21 June 2017) <https://deepmind.com/blog/article/taunton-and-somerset-nhs-foundation-trust-partnership> accessed 17 August 2020; 'Bringing Streams to Yeovil District Hospital NHS Foundation Trust' (*DeepMind Blog*, 5 November 2017) <https://deepmind.com/blog/announcements/bringing-streams-yeovil-district-hospital-nhs-foundation-trust> accessed 17 August 2020.
[30] 'Excited to announce a new medical partnership with DeepMind Health' (18 September 2019) <www.moorfields.nhs.uk/content/excited-announce-new-medical-research-partnership-deepmind-health> accessed 10 August 2020.
[31] University College London Hospitals NHS Foundation Trust 'Research begins to develop pioneering technology to plan radiotherapy treatment' (30 August 2016) <www.uclh.nhs.uk/News/Pages/Researchbeginstodeveloppioneeringtechnologytoplanradiotherapytreatment.aspx> accessed 17 August 2020.

College London NHS Foundation Trust to explore how AI could improve breast cancer screening.[32]

Privacy controversies were largely circumvented in these subsequent deals through the anonymisation of patient data, the publication of contracts online, and the provision of opt-out procedures for patients.[33] Despite this, DeepMind's work with the Royal Free had drawn the attention of many to the limitations of and loopholes in data protection law as it applies to new forms of research partnerships between public health providers and technology companies, as well as the tech giants' burgeoning interest in NHS patient data.

1.1.3. Beyond privacy: the economic and political implications of DeepMind-NHS

Despite the predominant focus on questions of privacy and data protection in responses to the DeepMind-Royal Free collaboration, Powles and Hodson's' original article drew attention to a multitude of related yet less clearly identifiable concerns relating to the distribution of resources and knowledge in the partnership. The authors highlighted that DeepMind is set to retain ownership of all algorithms- and thus knowledge- developed through the collaboration,[34] raising questions around the

[32] Ryan O'Hare 'Research collaboration aims to improve breast cancer diagnosis using AI' (24 November 2017) <www.imperial.ac.uk/news/183293/research-collaboration-aims-improve-breast-cancer/> accessed 17 August 2020.
[33] 'Deepmind Health Q&A | Moorfields Eye Hospital NHS Foundation Trust' <www.moorfields.nhs.uk/faq/deepmind-health-qa> accessed 20 November 2017; 'Deepmind Q And A' <www.uclh.nhs.uk/OurServices/ServiceA-Z/Cancer/RADIO/Pages/DeepMindQandA.aspx> accessed 20 November 2017.
[34] Powles & Hodson (n2) 362, 357.

future costs of the company's technologies, the value flowing to UK taxpayers, and the seeming prioritization of private over public interests.[35]

They further highlighted the secretive nature of the partnership and the so-called 'transparency paradox' or 'one-way mirror' surrounding the operations of the technology giants like Google, which is facilitated by commercial confidentiality protections and insufficient corporate public law obligations.[36] The authors also argued that the partnership failed both to engage with NHS patients and consult with relevant regulatory organisations, with due diligence amounting to "a post-hoc and inadequate privacy impact assessment".[37] They also expressed scepticism about the effectiveness of DeepMind's Independent Review Panel (IRP), stating that holding technology companies like Google to account is "one of the most pressing political challenges we face today".[38]

Their criticisms invoke topical scholarly debates around the benefits and risks of public-private partnership,[39] the political economy of health data,[40] and the broader implications of Big Tech's expansion into the healthcare domain.[41] Despite this, when I commenced my research on the DeepMind-NHS partnership in June 2017, such issues were peripheral in public and scholarly discussion surrounding the partnership by comparison to privacy concerns. This privacy centrism was reflected

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[35] ibid 362.
[36] ibid 360.
[37] ibid 357.
[38] ibid 361.
[39] Graham A. Hodge & Carston Greve (eds) *The challenge of public-private partnerships: learning from international experience* (Edward Elgar Publishing, 2005); Derick W. Brinkerhoff and Jennifer M. Brinkerhoff 'Public-private partnerships: Perspectives on purposes, publicness, and good governance' (2011) Public Adm Dev 31(1) 2-14; Mariana Mazzucato *The Entrepreneurial State: debunking public vs. private sector myths* (Anthem Press, 2013).
[40] Barbara Prainsack 'The political economy of digital data: introduction to the special issue' (2020) Policy Study J DOI: 10.1080/01442872.2020.1723519; Kean Birch et al 'The problem of innovation in technoscientific capitalism: data rentiership and the policy implications of turning personal digital data into a private asset' (2020) Policy Stud J DOI: 10.1080/01442872.2020.1748264.
[41] Tamar Sharon 'The Googlization of health research: from disruptive innovation to disruptive ethics' (2016) J Pers Med 13(6) 563-574; Tamar Sharon 'When digital health meets digital capitalism, how many common goods are at stake?' (2018) Big Data Soc 5(2).

in analysis of the human rights implications of DeepMind-NHS collaboration, which articulated its impacts almost exclusively in terms of privacy risks.[42]

This focus on privacy- at the expense of other relevant human rights issues- reflects a broader trend both within and beyond human rights scholarship on commercial data-driven health research. In part, this may reflect the fact that privacy is often framed in terms of *individual* harm and human rights *violations*; the impacts of data-driven health research on privacy are therefore more easily identifiable and immediately intrusive for patients than the kinds of *systemic* harms and soft *impacts* associated with socioeconomic rights like the right to health.[43] This could also reflect the highly sensitive nature of health data, which may elicit a particularly strong and emotive desire for privacy by comparison other forms of data. Further to this, conversations around the human rights impacts of data practice and new technologies frequently take place in silos, with discussions on privacy often remaining separate from discussions on other human rights, exacerbating disparities between them.[44]

Despite the prevalence of privacy-centrism in discussions around DeepMind-NHS and commercial data-driven health research more broadly, Powles and Hodson's concerns about the broader economic and political dimensions of the partnership indicate it may have significant ramifications for other human rights, notably the human right to health. The problematic aspects of intellectual property (IP) regimes and their implications for access to technologies in the pharmaceutical

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[42] Big Brother Watch 'NHS, DeepMind and the ICO: the Importance of Privacy in a Modern NHS' (*Big Brother Watch Blog*, 6 July 2017) <https://bigbrotherwatch.org.uk/2017/07/nhs-deepmind-and-the-ico-the-importance-of-privacy-in-a-modern-nhs/> accessed 7 September 2020; Basu (n5).

[43] Tsjalling Swierstra & Hedwig te Molder, 'Risk and Soft Impacts', in S Roeser et al, (eds.) 'Handbook of Risk Theory' (2012, Springer), available at < https://link.springer.com/referenceworkentry/10.1007%2F978-94-007-1433-5_42 > (accessed 21 June 2021).

[44] UNHRC, 'Possible impacts, opportunities and challenges of new and emerging digital technologies with regard to the promotion and protection of human rights' (19 May 2021) UN Doc A/HRC/47/52.

sector, for example, have been criticised by right to health scholars and practitioners.[45] Furthermore, issues relating to the transparency and accountability of the DeepMind-NHS collaboration implicate not only the state's obligations with respect to the right to health but also topical debates in the business and human rights (BHR) movement around the right to health obligations of commercial actors.[46] This suggests that the DeepMind-NHS partnership may have significant and as-of-yet unexplored implications for the right to health that warrant further investigation.

1.2. Research aims and questions

My overarching research question is:

"What are the right to health implications of data-driven research partnerships which enable commercial technology companies to access patient data from the NHS in the United Kingdom?"

This research question encompasses three primary research aims:

[45] UNHRC 'Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover' (31 March 2009) UN Doc A/HRC/11/12; Anand Grover et al 'Pharmaceutical companies and global lack of access to medicines: strengthening accountability under the right to health' (2012) J Law Med Ethics 40(2) 234-250; Joo-Young Lee & Paul Hunt 'Human rights responsibilities of pharmaceutical companies in relation to access to medicines' (2012) J Law Med Ethics 40(2) 220-233.

[46] For state obligations, see UNHRC, 'General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)' (2000) UN Doc E/C.12/2000/4. For topical debates in business and human rights, see Florian Wettstein 'CSR and the debate on business and human rights' (2012) Bus Ethics Q 22(4) 739-770; Surya Deva 'Treating human rights lightly: a critique of the consensus rhetoric and the language employed by the Guiding Principles' in Surya Deva & Dan Bilchitz (eds) *Human Rights Obligations of Business: beyond the Corporate Responsibility to Respect?* (Cambridge University Press, 2013) 78-104; Jernej Letnar Černič & Tara Van Ho (eds) *Human Rights and Business: Direct Corporate Accountability for Human Rights* (Wolf Legal Publishers, 2015).

a. To analyse the political economy of the DeepMind-NHS partnership
b. To explore the implications of the political economy of the DeepMind-NHS partnership for the right to health
c. To consider how future data-driven research partnerships like DeepMind-NHS can advance the right to health.

1.3. Academic context

1.3.1. Public-private partnerships

Public-private partnerships (PPPs) are "cooperative institutional arrangements between public and private sector actors".[47] In the health sector, this term encompasses a wide array of different models including PPPs for health infrastructure and services- such as the Private Finance Initiatives (PFI)- global health partnerships (GHPs), and the so-called 'implicit' PPP involved in pharmaceutical research and development (R&D). PPPs share a common philosophy; that they promote shared risk-taking and innovation and are mutually beneficial to both public and private sectors.[48] The PPP paradigm is thus rooted in neoliberal and managerialist theory, which conceptualises privatisation as the solution to public sector lethargy and bureaucracy.[49]

[47] Hodge & Greve (n39) 1.
[48] ibid 4.
[49] Patrick Dunleavy et al 'New Public Management is Dead- Long Live Digital-era Governance' (2005) JPART 16 467-494.

However, PPPs across the health sector have been subject to criticisms that challenge their underlying economic rationale. Though PPPs promise to deliver value for money (VfM), critics highlight how the problematic aspects of PPP appraisal,[50] the underappreciated role of the state,[51] and the prioritisation of financial metrics over broader considerations of social value and the public interest cast doubt on this assumption.[52] Furthermore, though equity is often an explicit objective in PPPs,[53] there is evidence to suggest that PPPs may prioritise corporate profit-making over the public health of the vulnerable and risk undermining broader health systems strengthening.[54]

PPPs in health have also faced criticism for lacking transparency and accountability. Complex organisational structures,[55] public and private sector opacity,[56] and the lack of oversight and accountability mechanisms surrounding

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[50] Jean Shaoul 'The Private Finance Initiative or the public funding of private profit?' in Graham D. Hodge & Carsten Greve (eds) *The challenge of public-private partnerships: learning from international experience* (Edward Elgar Publishing, 2005) 190-208; Jean Shaoul 'A critical financial analysis of the Private Finance Initiative: selecting a financing method or allocating economic wealth?' (2005) Crit Perspect Account 16(4) 441-471; Graeme Hodge & Carsten Greve 'Public-private partnerships: governance scheme or language game' (2010) Aust J Public Adm 69:S8-22.

[51] Mazzucato (n39); Linsey McGoey 'The philanthropic state: market-state hybrids in the philanthrocapitalist turn' (2014) Third World Q 35(1) 109-125.

[52] Judith Richter 'Public-private Partnerships for Health: A trend with no alternatives?' (2004) Development 47(2) 43-48; Brinkerhoff & Brinkerhoff (n39); Anthony E. Boardman & Aidan R. Vining 'The political economy of public-private partnerships and analysis of their social value' (2012) Ann Public Coop Econ 83(2) 177-141

[53] Brinkerhoff & Brinkerhoff (n39)

[54] Shaoul 'The Private Finance Initiative or the public funding of private profit?' (n48); Bridget Pratt & Bebe Loff 'Health research systems: promoting health equity or economic competitiveness?' (2012) B World Health Organ 90 55-6; Arne Ruckert & Ronald Labonté 'Public-private partnerships (PPPs) in global health: the good, the bad and the ugly' (2014) Third World Q 35(9) 1598-1614; Jocalyn Clark & Linsey McGoey 'The black box warning on philanthrocapitalism' (2016) Lancet 388(10059) 2457-2459.

[55] Kent Buse & Gill Walt 'Global public-private partnerships: part I-a new development in health?' (2000) Bull World Health Organ 78 549-61; Matthew Flinders 'The politics of public-private partnerships' (2005) Br J Politics Int Relat 7(2) 215-239; John Hood et al 'Transparency of risk and reward in UK public-private partnerships' (2006) Public Budg Finance 26(4) 40-58

[56] Hodge & Greve (n39); Shaoul 'The Private Finance Initiative or the public funding of private profit?' (n48); Flinders (n53); Hood et al (n53); Linsey McGoey 'Philanthrocapitalism and its critics' (2012) Poetics 40(2) 185-199; UCL Institute of Innovation and Public Purpose 'The people's prescription: re-imagining health innovation to deliver public value' (2018) IIPP Policy Report 2018-10 <https://www.ucl.ac.uk/bartlett/public-purpose/sites/public-purpose/files/peoples_prescription_report_final_online.pdf> accessed 6 August 2020.

PPPs all pose substantial barriers to democratic accountability.[57] Additionally, many critics draw attention to the ways in which PPPs facilitate the covert expansion of private power through obfuscation of the public-private sector distinction,[58] risking corporate bias and regulatory capture and enabling commercial actors to exert undue influence over research agendas in global health.[59] These criticisms imply that the PPP model may necessitate trade-offs between its purported benefits and good governance principles like transparency and accountability.

Scholarly critique of PPPs in health thus calls into question the philosophy and rationale underlying PPPs, highlighting the need for close scrutiny of PPPs' purported benefits. Furthermore, it suggests that PPPs are simultaneously redefining and obscuring the distinction between public and private sectors in health, resulting in "a transfer of rights and control away from the public sphere: vesting greater authority, decision-making, and power over important social concerns in the hands of private, unaccountable market actors".[60] Finally, the diversity of PPP forms and their underlying commonalities point to the 'politicisation' of the PPP paradigm,[61] which has evolved and adapted over time and space to serve the political ends of those who wish to employ it.

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[57] Graeme Hodge 'Accountability in the privatised state: The changing of the guardians' (2004) Altern Law J 29(1) 4-9; Hood et al (n53); Sherri A. Brown 'The Partnership Prescription: Access to HIV/AIDS-related Medicines and Public-Private Partnerships' in Sandra J. MacLean, Sherri A. Brown & Pieter Fourie (eds) *Health for Some* (Palgrave Macmillan, 2009) 210-224.
[58] Richter (n50); Ruckert & Labonté (n52).
[59] Buse & Walt (n55); Shaoul 'The Private Finance Initiative or the public funding of private profit?' (n50); John Abraham 'The pharmaceutical industry, the state and the NHS' in Jonathan Gabe & Michael Cainan (eds) *The New Sociology of the Health Service* (Routledge, 2009); Todd Faubion et al 'Co-Opting the Global Health Agenda: The Problematic Role of Partnerships and Foundations' in Rushton, S & Williams, O D (eds), *Partnerships and Foundations in Global Health Governance* (Palgrave Macmillan, 2011) 209-227; Clark & McGoey (n54); Michael R. Reich 'The core roles of transparency and accountability in the governance of global health public-private partnerships' (2018) Health Syst Reform 4(3) 239-248.
[60] Heather Whiteside 'Unhealthy policy: The political economy of Canadian public-private partnership hospitals' (2011) Health Sociol Rev 20(3) 258-268, 259.
[61] Hodge & Greve (n39)

This scholarship also reveals gaps in our understanding of the normative dimensions of PPP, of specific case studies of PPP, and of new forms of partnership emerging in the health sector. The focus of my study- the DeepMind-NHS partnership- is one such novel iteration of the PPP model. Much like public-private collaboration in the pharmaceutical and global health sectors, data-driven research partnerships like DeepMind-NHS are justified on the basis that they promote mutually-beneficial health innovation. However, the DeepMind-NHS partnership is also distinct from the forms of partnership discussed here in that it necessitates the sharing of health data. The emergence of the so-called 'data economy' underlying the revolution in data-driven and automated technological innovation is a paradigm shift with significant implications for the relationship between the public and private sectors and the dynamics of innovation. For this reason, I turn to the emerging sociological field of critical data studies (CDS) to contextualise the DeepMind-NHS partnership in the political economy of health data.

1.3.2. The Political Economy of Health Data

Among CDS scholars, there is growing recognition of the commercial value of data as a financial asset in the knowledge economy.[62] This paradigm economic shift has been accompanied by the increasing transformation of health data from a source of personal information into a commercially-valuable asset. This shift is being driven

[62] Rob Kitchin & Tracey Lauriault 'Towards Critical Data Studies: Charting and Unpacking Data Assemblages and Their Work' (2014) The Programmable City Working Paper 2, pre-print version of chapter to be published in Jim Eckert, Andrew Shears & Jim Thatcher (eds) *Geoweb and Big Data* (University of Nebraska Press) <https://papers.ssrn.com/sol3/papers.cfm?Abstract_id=2474112> accessed 21 September 2020; Kean Birch 'Technoscience Rent: Towards a Theory of Rentiership for Technoscientific Capitalism' (2019) Sci Technol Hum Values 45(1) 3-33; Prainsack (n40).

primarily by the business models of Big Tech- that is, Google, Amazon, Facebook and Apple- who rely on access to data to derive predictive insights and build new algorithmic technologies.[63] Big Tech's platform monopolies are increasingly expanding into new fields like healthcare,[64] with the promise of applying their innovative capabilities to develop data-driven healthcare tools to meet public health needs.

However, CDS scholars have raised serious concerns around the distributive implications of data-driven health research. Some argue that the economic properties of digital markets,[65] the 'data extractive' business models of the platform monopolies,[66] and the growing phenomenon of 'data rentiership'[67] fuel corporate wealth extraction on an unprecedented scale. As a result, commercial access to health data risks generating inequities on the basis of capability to afford access to data-driven health products.[68] Fuelling these distributive injustices is an underlying tension between the commercial and public value of health data,[69] which means that data-driven health research inherently necessitates trade-offs.[70]

The power and political influence of Big Tech is a further source of concern in the CDS literature. The 'one-way mirror' that enables these companies to operate in

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[63] Evgeny Morozov 'There is a leftwing way to challenge big tech for our data. Here it is' (*The Guardian*, 19th August 2018) <www.theguardian.com/commentisfree/2018/aug/19/there-is-a-leftwing-way-to-challenge-big-data-here-it-is> accessed 21st September 2020; Shoshana Zuboff *The Age of Surveillance Capitalism: The Fight for a Human Future at the New Frontier of Power* (Profile Books, 2019).
[64] Tamar Sharon 'The Googlization of health research...' (n41); Prainsack (n40).
[65] Mariana Mazzucato *The value of everything: Making and taking in the global economy* (Hachette UK, 2018).
[66] Morozov (n63).
[67] Birch et al (n40).
[68] Bronwyn Parry & Beth Greenhough *Bioinformation* (Polity, 2017).
[69] Ibid; Mhairi Aitken et al 'Who benefits and how? Public expectations of public benefits from data-intensive health research' (2018) Big Data Soc July-December 2018 1-12; Barbara Prainsack 'Logged out: Ownership, exclusion and public value in the digital data and information commons' (2019) Big Data Soc Jan-June 2019 1-15.
[70] Sharon 'When digital health meets digital capitalism...' (n41); Alessandro Blasimme et al 'Big Data, precision medicine and private insurance: A delicate balancing act' (2019) Big Data Soc Jan-June 2019 1-6.

secret,[71] their political influence,[72] growing engagement with 'ethical' capitalism,[73] and lack of accountability together place Big Tech in a position of unprecedented power and political influence.[74] Furthermore, Google has particularly caught the attention of critical scholars due to the company's benevolent image obscuring its underlying commercial interests,[75] its growing monopoly powers and lack of accountability,[76] and expansion into healthcare markets.[77]

This body of literature reveals the emergence of "new constellations of actors and power" in data-driven health research, [78] through which the public and private, ethical and unethical, and profit and not-for-profit have become increasingly intertwined.[79] Furthermore, it highlights the need to move beyond an individualistic, privacy-oriented focus in CDS to consider the collective implications of the data economy.[80]

These issues raise ethical dilemmas and pose novel regulatory challenges with significant ramifications for the normative underpinnings and legal framework of human rights. The following section reviews the human rights scholarship on commercial data-driven health research, situating the DeepMind-NHS partnership in

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[71] Frank Pasquale *The black box society* (Harvard University Press, 2015).
[72] Paul Nemitz 'Constitutional democracy and technology in the age of artificial intelligence' (2018) Phil Trans R Soc A 376 20180089; Mary Ebeling 'Patient disempowerment through the commercial access to digital health records' (2019) Health 23(4) 385-400; Corinne Cath 'Governing artificial intelligence: ethical, legal and technical opportunities and challenges' (2019) Phil Trans R Soc *A* 376 20180080; Barbara Prainsack 'The value of healthcare data: to nudge, or not?' (2020) Policy Study J DOI: 10.1080/01442872.2020.1723517.
[73] Siva Vaidhyanathan *The Googlization of everything (and why we should worry)* (Univ of California Press, 2012); Barbara Prainsack *Personalized medicine: empowered patients in the 21st century?* Vol 7 (NYU Press, 2017); Sharon 'When digital health meets digital capitalism...' (n41); Cath (n72); Nemitz (n72); Bernard Arogyaswamy 'Big tech and societal sustainability: an ethical framework' (2020) AI & Soc 1-12.
[74] Zuboff (n63); Prainsack (n69); Barbara Prainsack 'Data Donation: How to Resist the iLevithian' in Jenny Krutzinna & Luciano Floridi (eds) *The Ethics of Medical Data Donation* Philosophical Studies Series 137 (Springer, 2019); Arogyaswamy (n73).
[75] Vaidhyanathan (n73).
[76] Vaidhyanathan (n73); Prainsack (n73); Zuboff (n63).
[77] Sharon 'The Googlization of health research...' (n41).
[78] Prainsack (n40) 2.
[79] Sharon 'When digital health meets digital capitalism...' (n41).
[80] Mark Andrejevic 'The Big Data Divide' (2014) Int J Commun 8 1673-1689; Prainsack (n72).

the context of the human rights scholarship on health data misuse, commercialization and profiteering.

1.3.3. The human rights implications of commercial data-driven health research

There is now widespread acknowledgement among human rights practitioners and scholars that the development and implementation of new data-driven technologies has significant implications for human rights.[81] Though much of the recent focus has been on AI,[82] some human rights scholars- particularly advocates of the rights to privacy and science- have turned their attention to the process of developing data-driven technologies; that is, to the process of data-driven research itself.

The right to privacy has received particular attention in the context of health data; this is exemplified by the establishment of a new United Nations (UN) special procedure- the Special Rapporteur on the Right to Privacy in the Digital Age- and his work to define the scope of the right to privacy in relation to health data.[83]

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[81] UN OHCHR 'The Right to Privacy in the Digital Age' <www.ohchr.org/EN/Issues/DigitalAge/Pages/DigitalAgeIndex.aspx> accessed 7 August 2020; 'How AI affects human rights' <www.hrbdt.ac.uk/what-we-do/how-ai-affects-human-rights/> accessed 5 August 2020; 'Research track: human rights & data' <https://datasociety.net/research/human-rights-data/> accessed 5 August 2020.

[82] Mark Latonero 'Governing artificial intelligence: Upholding human rights and dignity' Data and Society (2018) 1-37; Lorna McGregor et al 'International human rights law as a framework for algorithmic accountability' (2019) ICLQ 68 309-343

[83] UN OHCHR 'Special Rapporteur on the right to privacy' <https://www.ohchr.org/en/issues/privacy/sr/pages/srprivacyindex.aspx> accessed 5 August 2020; UN OHCHR 'End of Mission Statement of the Special Rapporteur on the Right to Privacy at the Conclusion of his Mission to the United Kingdom of Great Britain and Northern Ireland' (29 June 2018) <www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=23296&LangID=E> accessed 5 August 2020; UNGA 'Right to privacy: Note by the Secretary General' (5 August 2019) UN Doc A/74/277.

Furthermore, civil and political rights scholars have highlighted the close relationship between health data misuse and the right to privacy,[84] the importance of transparency and accountability in facilitating public trust in this context,[85] and the close links between the right to privacy and other civil and political and economic, social and cultural rights with regards to health data misuse.[86]

By contrast, scholarship on health data commercialization and profiteering has tended to focus on the implications of data-driven health research for the right to science. The right to science is a useful framework to conceptualise these issues as there is a wealth of UN-level guidance and academic scholarship surrounding issues like IP, equity and access to technologies in the context of scientific research.[87] The relationship between commercial data-driven health research and the right to science has primarily been theorized by scholars like Knoppers and Harris and Wyndham,[88] who emphasise the state's positive obligations.[89] Right to science

[84] Edward S. Dove & Vural Özdemir 'What role for law, human rights and bioethics in an age of big data, consortia science and consortia ethics? The importance of trustworthiness' (2015) Laws 4(3) 515-540.
[85] Ibid; Effy Vayena & John Tasioulas The dynamics of big data and human rights: the case of scientific research' (2016) Phil Trans R Soc A 374 20160129.
[86] Di Iorio et al 'Health research and systems' governance are at risk: should the right to data protection override health?' (2014) J Med Ethics 40 488-492; Tom Chan et al 'The UK National Data Guardian for health and care's review of data security, consent and opt-outs: leadership in balancing public health with rights to privacy' (2016) BMJ Health Care Inform 23(3) DOI:10.14236/jhi.v23i3.909.
[87] UN level guidance includes UN CESCR, 'Human rights and intellectual property: Statement by the Committee on Economic Social and Cultural Rights' (14 December 2001) UN Doc E/C.12/2001; UNHRC 'Report of the Special Rapporteur in the field of cultural rights, Farida Shaheed: Copyright policy and the right to science and culture' (24 December 2014) UN Doc A/HRC/28/57; UN CESCR 'General comment No.25 (2020) on science and economic, social and cultural rights (article 15(1) (b), (2), (3) and (4) of the International Covenant on Economic, Social and Cultural Rights)' (2020) UN Doc E/C.12/GC/25. Scholarship includes Yvonne Donders 'The right to enjoy the benefits of scientific progress: in search of state obligations in relation to health' (2011) Med Health Care and Philos 14 371-381; Sebastian Porsdam Mann & Maximillian M. Schmid 'Health Research Priority Setting: State Obligations and the Human Right to Science' (2018) Am J Bioeth 18(11) 33-35.
[88] See Bartha M. Knoppers et al 'A human rights approach to an international code of conduct for genomic and clinical data sharing' (2014) J Hum Genet 133(7) 895-903; Theresa L. Harris & Jessica M. Wyndham 'Data rights and responsibilities: a human rights perspective on data sharing' (2015) J Empir Res Hum Res Ethics 10(3) 334-337.
[89] Knoppers et al (n88); Harris & Wyndham (n88); Bartha M. Knoppers & Adrian Mark Thorogood 'Ethics and Big Data in health' (2017) Curr Opin Cell Biol 4 53-57.

scholars further highlight the importance of tackling issues surrounding IP,[90] equity,[91] transparency,[92] and accountability in data-driven health research,[93] and the close relationship between the right to science and socio-economic rights like the right to health.[94]

Some of these scholars draw attention to the relevance of the right to health in relation to commercial data-driven health research;[95] furthermore, many of the issues this literature uncovers relate to cross-cutting human rights principles that are also fundamental components of the right to health. The UN Committee on Economic, Social and Cultural Rights' (CESCR) General Comment 25 has reaffirmed the importance of this connection between the right to health and data-driven innovation, implying it may be an important area of critical enquiry for right to health scholars.[96]

Despite this, the relationship between commercial data-driven health research and the right to health has received inadequate attention. The most significant scholarly contribution in this area- the Health and Human Rights Journal Special Issue on Big Data, Technology, Artificial Intelligence, and the Right to Health-[97] raises many pertinent issues related to commercial data-driven health research, including issues of access to technology, the human rights obligations of commercial actors, and right to health due diligence for AI projects.[98] However, besides my own

[90] Vayena & Tasioulas (n85).
[91] Harris & Wyndham (n88); Knoppers & Thorogood (n89).
[92] Ibid.
[93] Ibid.
[94] Knoppers et al (n88).
[95] Ibid; Carole J. Petersen 'Big Data, Health Care, and International Human Rights Norms' (2017) Asia Pacific J Health L & Ethics 11(1) 1-22.
[96] CESCR General Comment 25 (n87).
[97] 'Special Section: Big Data, Technology, Artificial Intelligence and the Right to Health' (2020) HHR Journal 22(2 available at < https://www.hhrjournal.org/volume-22-issue-2-december-2020/> (accessed 19 June 2021)
[98] Sara L.M. Davis & Carmel Williams 'Enter the Cyborgs: Health and Human Rights in the Digital Age' (2020) HHR Journal 22(2): 1- 6; Carmel Williams, 'A Health Rights Impact Assessment Guide for

contribution on the commercialization of health data, none of the papers focus specifically on the implications of commercial data-driven health research for the right to health.[99] Furthermore, there is an absence of in-depth case studies exploring the relationship between big data, AI and the right to health, with most relevant scholarship focused on broadly summarising key issues or developing due diligence mechanisms.

1.4. Theoretical framework- the right to health and the business and human rights framework

My thesis explores the DeepMind-NHS case through the legal framework of the right to health and business and human rights. I chose to incorporate the business and human rights framework into my analysis in addition to the right to health because of the critical role of Google- a commercial actor- in the DeepMind-NHS partnership. The BHR framework provides a legal framework through which technology companies' right to health responsibilities are conceptualised and operationalised. Incorporating the BHR framework into my theoretical framework thus enables me to determine the right to health responsibilities of Google under DeepMind-NHS and assess the company's adherence to these responsibilities in practice, ensuring that my work places equal emphasis on the importance of the

Artificial Intelligence Projects' (2020) HHR Journal 22(2): 55-62; Nina Sun, et al, 'Human Rights and Digital Health Technologies' (2020) HHR Journal 22(2): 21-32; Sharifah Sekalala, et al, 'Analyzing the Human Rights Impact of Increased Digital Public Health Surveillance during the COVID-19 Crisis" (2020) HHR Journal 22(2): 7-20.

[99] Amy Dickens, 'From Information to Valuable Asset: The Commercialization of Health Data as a Human Rights Issue' (2020) HHR Journal 22(2): 67-69.

responsibilities of commercial actors in realising human rights as the obligations of states.

In applying this theoretical framework to the DeepMind-NHS case, I focus on the following elements: AAAQ and the principle of equity, maximum available resources (MAR), state accountability for the right to health and corporate responsibility for the right to health. These elements are closely related to political economic questions of resource and knowledge distribution and are therefore particularly relevant to my interdisciplinary analysis of the DeepMind-NHS case study.

This section introduces the right to health and the business and human rights movement and briefly summarises the key elements of the framework on which my thesis will focus.

1.4.1. The right to health

The right to the highest attainable standard of health (or right to health) was first delineated in the 1946 World Health Organisation (WHO) constitution and Article 25(1) of the 1948 Universal Declaration of Human Rights (UDHR),[100] a globally applicable set of standards underpinning the international human rights movement. However, it was the adoption of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) in 1966 that enshrined the right to health in an international, legally binding treaty for the first time.[101] The right to health has since

[100] WHO, 'Constitution of the World Health Organisation' (1946) <http://www.who.int/governance/eb/who_constitution_en.pdf> accessed 21 November 2017; Universal Declaration of Human Rights (adopted 10 December 1948) UNGA Res 217 A(III) (UDHR).
[101] International Covenant on Economic, Social and Cultural Rights (adopted 16 December 1966, entered into force 3 January 1976) 993 UNTS 3 (ICESCR).

been included in a number of international and regional human rights treaties.[102] Furthermore, at the domestic level, the right to health has been incorporated into many national constitutions.[103] Most states have ratified the ICESCR, and those that haven't have signed at least one of the other treaties containing the right to health; thus, all states have- to a greater or lesser degree- accepted the right to health.[104]

Implementation of the right to health under the ICESCR is overseen by independent monitoring body, the CESCR. In 2000, the CESCR published General Comment 14,[105] the first ground-breaking and authoritative explication of the right to health under the ICESCR. The promotion and protection of the right to health has been further strengthened by the establishment of a special procedure on the right to health in 2002, which saw the appointment of the first Special Rapporteur on the Right to the Highest Attainable Standard of Health, Paul Hunt. Hunt and his successors have reported annually to the UN Human Rights Council and General Assembly, refining the context and scope of the right to health and identifying key

[102] International treaties include Convention on Rights of a Child (adopted 20 November 1989, entered into force 2 September 1990) 1577 UNTS 3 (CRC); Convention on the Elimination of All Forms of Discrimination Against Women (adopted 18 December 1979, entered into force 3 September 1981) 1249 UNTS 13 (CEDAW); International Convention on the Elimination of all Forms of Racial Discrimination (adopted 21 December 1965, entered into force 4 January 1969) 660 UNTS 195 (CERD); Convention on the Rights of Persons with Disabilities (adopted 24 January 2007) A/RES/61/106 (CRPD). Regional treaties include African Charter on Human and Peoples' Rights (adopted 27 June 1981, entered into force 21 October 1986) (1982) 21 ILM 58 (African Charter); African Charter on the Rights and Welfare of the Child (adopted 11 July 1990, entered into force 29 November 1999) (1990) CAB/LEG/24.9/49; European Social Charter (adopted 3 May 1996, entered into force 1 July 1999) ETS 163; Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador) (entered into force 16 November 1999) OAS Treaty Series No 69 (1988). For national constitutions, see Gunilla Backman et al 'Health Systems And The Right To Health: An Assessment Of 194 Countries' (2008) Lancet 372(9655) 2047-2085.
[103] Backman et al (n102).
[104] Backman et al (n102).
[105] General Comment 14 (n46).

right to health issues,[106] and made numerous country visits, identifying critical health issues around the world and promoting the right to health internationally.[107]

Article 12(1) of the ICESCR states that, “The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.[108] Critically, the right to health should not be confused with the right to be healthy; factors like genetic susceptibility to illness, for example, are beyond the government’s control.[109] Instead, the right to health should be understood as “the right to an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to national and local priorities, and accessible to all”.[110]

The underlying determinants of health refers to other socio-economic factors that promote conditions in which people can lead a healthy life.[111] General Comment 14 draws attention to the importance of these underlying determinants- which include food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment- and stresses the interrelatedness of the right to health and other human rights.[112] Non-discrimination and equality are also key underlying principles of the right to health,

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[106] UNCHR ‘Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31’ (13 Feb 2003) UN Doc E/CN.4/2003/58; UNGA ‘Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ (11 August 2014) UN Doc A/69/299. See also ‘Annual Reports’ <http://www.ohchr.org/EN/Issues/Health/Pages/AnnualReports.aspx> accessed 31 May 2018.
[107] Navanethem Pillay 'Right To Health And The Universal Declaration Of Human Rights' (2008) Lancet 372(9655) 2005-6.
[108] ICESCR (n101), art 12(1).
[109] Helen Potts 'Accountability And The Right To The Highest Attainable Standard Of Health' (2008) University of Essex Human Rights Centre <http://repository.essex.ac.uk/9714/1/participation-right-highest-attainable-standard-health.pdf> accessed 7 August 2020.
[110] Ibid.
[111] General Comment 14 (n46).
[112] Ibid para 3.

requiring that states do not discriminate on the grounds of sex, race, age, language, disability, health status, sexual orientation, or socio-economic or other status in the provision of health care.[113]

Like all economic, social and cultural rights, the right to health places a tripartite obligation on the state to respect, protect, and fulfil the right to health;[114] this inhibits the state from denying or limiting equal access for all persons, requires the state to prevent third parties from compromising the health of others, and necessitates the adoption of measures to guarantee the full realisation of the right to health.[115]

1.4.2. The business and human rights movement

Though the UN's engagement with business and human rights (BHR) stretches back as far as the 1970s,[116] the business and human rights movement came to prominence in the 1990s as the culmination of a number of related events.[117] Crucially, a proliferation of cases implicating corporations in gross human rights violations by security forces and repressive governments- combined with a number of new cases being filed against corporations involved in WWII and growing scrutiny of the apparel, footwear and technology sectors- highlighted the need for the

[113] Ibid.
[114] Ibid.
[115] Ibid.
[116] Surya Deva & David Bilchitz 'The human rights obligations of business: a critical framework for the future' in Surya Deva & David Bilchitz (eds) *Human rights obligations of business: beyond the corporate responsibility to protect* (Cambridge University Press, 2013) 1-26.
[117] Anita Ramasastry 'Corporate Social Responsibility Versus Business and Human Rights: Bridging the Gap Between Responsibility and Accountability' (2015) J Hum Rights 14(2) 237-259.

UN to pay greater attention to the relationship between commercial actors and human rights.[118]

The BHR movement "grows out of a quest for corporate accountability to mitigate or prevent the adverse impacts of business activity on individuals and communities and out of expectations grounded in a specific core set of human rights obligations".[119] It emerged predominantly from the field of international law and is therefore focused primarily on developing and enforcing legal solutions to corporate misconduct, with an emphasis on strengthening governmental oversight and facilitating remedy.[120] Furthermore, the movement's focus on fundamental human rights places emphasis on the injustice of corporate misconduct, thus framing corporate human rights responsibilities as indispensable and imperative obligations.[121]

These distinct features of BHR set it apart from the closely related field of corporate social responsibility (CSR). Despite both seeking to ensure that commercial actors engage in socially beneficial and responsible behaviour,[122] CSR focuses primarily on voluntary corporate beneficence and philanthropy and the idea that such activities are important to the success of commercial actors.[123] This reflects the movement's genesis in the field of business studies and the conceptualisation of the modern corporation as having ethical responsibilities beyond its shareholders and employees.[124] BHR and CSR are thus premised on differing notions of the

[118] Notable cases include Wiwa v. Royal Dutch Petroleum Co. 226 F.3d 88 (2d Cir. 2000) and Doe v. Unocal 395 F.3d 932 (9th Cir. 2002). See also Wettstein (n46); Ramasastry (n117).
[119] Ramasastry (n117) 238.
[120] Ramasastry (n117).
[121] Wettstein (n46).
[122] Ramasastry (n117).
[123] Wettstein (n46); Ramasastry (n117).
[124] Ibid.

primary responsible actors (state vs. corporation), sources of authority (law vs. ethics), and thus the strength of obligation (fundamental vs. voluntary).

Despite their differences, some early developments in the field of BHR- notably the UN Global Compact- also embodied elements of the CSR movement.[125] The UN Global Compact- introduced in 2000- is a voluntary initiative inviting corporations to adhere to ten (originally nine) principles, two of which include supporting and respecting human rights and preventing complicity in human rights violations[126]. Signatories report annually on progress towards fulfilling these principles, with the aim of rewarding good business practices and fostering mutual learning[127]. However, the Compact has faced criticism from human rights practitioners for lacking 'teeth', as companies found to be complicit in human rights violations are not excluded.[128] The initiative therefore demonstrated the limitations of CSR's corporate voluntarism and signalled the need for stronger human rights protections against commercial actors.

Partially in response to these shortcomings, in 2003, the United Nations Sub-Commission on the Promotion and Protection of Human Rights approved the draft *Norms on the Responsibilities of Transnational Corporations and Other Business Enterprises with Regard to Human Rights.*[129] The Draft Norms went further than the Global Compact in recognising that businesses have obligations to "promote, secure the fulfilment of, respect, ensure respect of and protect human rights";[130] they thus "represented a restatement of existing human rights obligations, found in diverse

[125] 'Homepage' <https://www.unglobalcompact.org> accessed 10 August 2020.
[126] 'The Ten Principles of the UN Global Compact' <https://www.unglobalcompact.org/what-is-gc/mission/principles> accessed 10th August 2020.
[127] Deva & Bilchitz (n116).
[128] Ramasastry (n117).
[129] UNCHR 'Norms on the Responsibilities of Transnational Corporations and Other Business Enterprises with Regard to Human Rights' (26 August 2003) UN Doc E/CN.4/Sub.2/2003/12/Rev.2.
[130] Ibid preamble para 3.

treaties, and an application of those principles to corporations".[131] The Draft Norms were deeply controversial; critics suggested they were too ambitious,[132] that the obligations delineated in the Norms could not apply to commercial actors,[133] and that the predominance of the views of experts- rather than states or corporations- meant they lacked widespread legitimacy among stakeholders.[134] The Norms were not approved by the UN Commission on Human Rights and were subsequently abandoned.

The shortcomings of the Norms highlighted the need for a human rights instrument that would receive more widespread endorsement from stakeholders in the BHR movement. In 2005, the UN Secretary General appointed Professor John Ruggie- the Global Compact's visionary- as Special Representative of the UN Secretary General on the issue of Human Rights and Transnational Corporations and Other Business Enterprises,[135] with a mandate to explore standards of corporate responsibility and accountability for human rights and the role of States in regulating and adjudicating business activities in this context.[136] In 2008, Ruggie's "protect, respect and remedy" framework was unanimously endorsed by the Human Rights Council and in 2011- following years of extensive consultation with a range of stakeholders- the framework was operationalised in the *Guiding Principles on Business and Human Rights for implementing the UN "Protect, Respect and Remedy" Framework* (hereafter the Guiding Principles).[137]

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[131] Ramasastry (n117).
[132] Jernej Letnar Černič & Tara Van Ho 'Introduction' in Jernej Letnar Černič & Tara Van Ho *Human Rights and Business: Direct Corporate Accountability for Human Rights* (Wolf Legal Publishers, 2015).
[133] Deva & Bilchitz (n116).
[134] Ramasastry (n117).
[135] Černič & Van Ho (n132).
[136] UN OHCHR Res 2005/69 (2005) UN Doc E/CN.4/RES/2005/69.
[137] UN OHCHR 'Guiding Principles on Business and Human Rights: Implementing the United Nations "Protect, Respect and Remedy" framework' (2011) UN Doc HR/PUB/11/04.

The Guiding Principles are generally considered the most authoritative delineation of the human rights obligations of corporations in international law.[138] They are intended as a tool "to provide practical guidance both to states and to companies, in order to ensure that all the instruments at the disposal of both shall be used to improve compliance with human rights in the activities of business".[139] Though not legally enforceable alone, the Guiding Principles are expected to be implemented by states and intergovernmental organisation through domestic or regional legislation.[140] In contrast to the proceeding Draft Norms, the Guiding Principles represent a 'bottom-up' approach to law making, which "allows... business organisations to play an unprecedented role in defining the contours of the rules that were to apply to them".[141] Ruggie aimed to achieve more widespread consensus through an approach based on 'principled pragmatism';[142] that is, a commitment to improving corporate compliance with human rights through the most practical means possible.

1.4.3. The right to health legal framework

1.4.3.1. AAAQ and the principle of equity

General Comment 14 sets out the 'AAAQ' framework, which describes four interrelated and essential elements of the right to health: the availability,

[138] Deva & Bilchitz (n116).
[139] Ibid.
[140] Černič & Van Ho (n132).
[141] Deva & Bilchitz (n116).
[142] UNCHR 'Interim report of the Special Representative of the Secretary-General on the issue of human rights and transnational corporations and other business enterprises' (22 Feb 2006) UN Doc E/CN.4/2006/97, para 81.

accessibility, cultural acceptability, and quality of health facilities, goods and services.[143] *Availability* requires the state to have functioning public health and health-care facilities, goods, services, and programmes in sufficient quantity. States must also ensure the *accessibility* of health facilities, goods, and services to all; this includes physical, economic, and information accessibility, as well as accessibility on the grounds of non-discrimination. Furthermore, health facilities, goods, and services must be culturally *acceptable*; that is, they must be culturally appropriate and respectful of medical ethics. Finally, they must also be good *quality* and scientifically and medically appropriate.[144]

General Comment 14 further prescribes that economic accessibility should be based on the principle of equity. This demands that "payment for health-care services, as well as services related to the underlying determinants of health... whether privately or publicly provided, are affordable for all, including socially disadvantaged groups",[145] such that, "poorer households should not be disproportionately burdened with health expenses as compared to richer households".[146] The concept of equity in human rights law is thus closely related to status and power,[147] social justice,[148] and the principles of non-discrimination and equality.[149] Though they are related, there is thus a crucial distinction between equity and equality; equity is an inherently normative concept, as it implies some kind of

[143] General Comment 14 (n46), para 12.
[144] General Comment 14 (n46).
[145] Ibid, para 12(b).
[146] Ibid.
[147] Audrey R. Chapman 'The social determinants of health, health equity, and human rights' (2010) Health Hum. Rights 12(2) 17-30.
[148] Paula Braveman & Sofia Gruskin 'Defining equity in health' (2003) J Epidemiol Commun H 57 254–258.
[149] Paula Braveman 'Health Disparities and Health Equity: Concepts and Measurement' (2006) Annu Rev Public Health 27 167–94.

judgement about whether the processes driving inequality are unjust or unfair,[150] whereas equality is "the metric by which health equity is assessed".[151]

1.4.3.2. Maximum available resources (MAR)

Article 2(1) of the ICESCR states that all signatories to the Covenant agree "to take steps, individually and through international assistance and co-operation, especially economic and technical, *to the maximum of its available resources*, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means...".[152] The duty to use maximum available resources (MAR) "means that a government must do all that it can to mobilize resources within the country in order to have funds available to progressively realise ESC rights".[153] This means governments have a legal obligation to use their resources both efficiently and effectively; that is, policies and programmes must be cost-effective, as well as delivering on their promise of improving human rights.[154] Where necessary, states also have a duty to provide international assistance to countries that do not have the resources to meet their socio-economic rights responsibilities.[155]

1.4.3.3. State accountability for the right to health

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[150] Braveman & Gruskin (n148).
[151] Paula Braveman 'Social conditions, health equity, and human rights' (2010) Health Hum Rights 12(2) 31-48.
[152] ICESCR (n101) Art 2(1).
[153] Ann Blyberg & Helena Hofbauer 'Article 2 & Governments' Budgets' (2014) <www.internationalbudget.org/wp-content/uploads/Article-2-and-Governments-Budgets.pdf> accessed 10 August 2020.
[154] Ibid.
[155] UNHRC 'General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant)' (1990) UN Doc E/1991/23.

In the context of the right to health, accountability refers to "the process which requires government to show, explain and justify how it has discharged its obligations regarding the right to the highest attainable standard of health".[156] Though definitions of accountability differ in the right to health scholarship, I adopt Williams and Hunt's tripartite conceptualisation of accountability as monitoring, review, and remedial action.[157]

States are required to monitor all aspect of policy development and implementation on a continuous basis;[158] reliable data is critical to this process,[159] as is transparency, which provides rights-holders with the information necessary to hold the state accountable for violations of the right to health.[160] Review has two components; analysis of the data collected through monitoring and assessment of whether commitments have been met.[161] Review should be independent, highlight successes and shortcomings, provide recommendations for improvement, and extend to non-state actors.[162] Finally, remedial action ensures that victims of violations of the right to health "should have access to effective judicial or other appropriate remedies at both national and international levels".[163]

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[156] Potts (n109).
[157] Carmel Williams & Paul Hunt 'Neglecting human rights: accountability, data and Sustainable Development Goal 3' (2017) Int J Hum Rights 21(8) 1114-1143.
[158] Shengnan Qiu & Gillian MacNaughton 'Mechanisms of Accountability for the Realization of the Right to Health in China' (2017) Health Hum Rights 19(1) 279–292.
[159] Williams & Hunt (n188).
[160] Qiu & MacNaughton (n189).
[161] Williams & Hunt (n188).
[162] WHO, 'Keeping Promises, Measuring Results' (Commission on Information and Accountability for Women's and Children's Health, Geneva, 2011) <www.who.int/topics/millennium_development_goals/accountability_commission/Commission_Report_advance_copy.pdf?ua=1> accessed 10 August 2020.
[163] General Comment 14 (n46).

Accountability relies on the establishment of accessible, transparent and effective accountability mechanisms.[164] An accountability mechanism is "the procedure through which government is answerable for its acts or omissions in relation to right to health obligations".[165] There are broadly five types of accountability mechanism; judicial, quasi-judicial, administrative, political and social.[166] Though accountability is frequently conflated with judicial accountability, non-judicial forms of accountability can also be effective, and different forms of accountability mechanism are mutually reinforcing and interdependent.[167]

States also have a duty to protect the right to health from commercial actors under the Guiding Principles. This obligates states to protect against corporate human rights abuses in their jurisdiction by "taking appropriate steps to prevent, investigate, punish and redress such abuse through effective policies, legislation, regulations and adjudication".[168] Operationalising the duty to protect requires that states enforce existing laws that require businesses to respect human rights- periodically assessing their adequacy and addressing any regulatory gaps- and ensure other laws governing businesses respect human rights.[169] The Guiding Principles also require states to provide guidance to businesses on how to respect human rights, which should indicate expected outcomes, facilitate sharing of best practices and advise on methods like due diligence procedures. Furthermore, States should encourage businesses to communicate how they address human rights issues; this can range from "informal engagement with affected stakeholders to

[164] Potts (n109).
[165] Ibid, 17.
[166] General Comment 14 (n46).
[167] Potts (n109).
[168] The Guiding Principles (n137) para 1.
[169] Ibid para 3.

formal public reporting"[170] and should account for risks to the safety of individuals, commercial confidentiality and the size and structure of the company.[171]

1.4.3.4. Corporate responsibility for the right to health

Under the Guiding Principles, the corporate responsibility to respect means businesses "should avoid infringing on the human rights of others and should address adverse human rights impacts with which they are involved".[172] This requires that commercial actors avoid contributing to negative human rights impacts and address them when they occur.[173] The Principles stress that these responsibilities apply to all business enterprises "regardless of their size, sector, operational context, ownership and structure";[174] however, they recognise that a company's ability to address adverse human rights impacts might vary according to these factors. The responsibility to respect must be operationalised through the appropriate policies and processes, including a policy commitment to respect human rights, a human rights due diligence process, and processes to enable the remediation of human rights violations.[175]

1.5. Contribution to the field

[170] Ibid.
[171] Ibid.
[172] The Guiding Principles (n137) para 11.
[173] Ibid para 13.
[174] Ibid para 14.
[175] Ibid para 15.

My thesis seeks to contribute to the field of human rights law by expanding the existing scope of human rights scholarship on health data and data-driven research, which has thus far focused predominantly on the rights to privacy and science. In doing so, I hope to determine the ramifications of data-driven research partnerships for the right to health, building upon the prefatory contributions of human right scholars and the CESCR in this area.[176]

By considering the distributive implications of the partnership and their impact on the right to health, I also hope to contribute to the existing right to health scholarship surrounding financial accessibility, equity and resource availability, situating relevant debates in the context of commercial data-driven health research. Additionally, in assessing the implications of knowledge asymmetries in the partnership for the right to health, I seek to further understanding of state accountability and corporate responsibility for the right to health, contributing to key debates in business and human rights around the nature and scope of corporate human rights responsibilities in international human rights law.

My thesis also contributes to political economic scholarship on PPPs. The PPP model has transmuted across space and time yet has faced common criticisms from political economists. My thesis seeks to develop critical political economic analysis of PPPs by focusing on a novel iteration of the PPP model- data-driven health research partnerships- highlighting commonalities and dissimilarities with other forms of PPP. In doing so, I hope to shed light on the distributive implications of the DeepMind-NHS partnership- and its ramifications for the credibility of the prevailing narrative of reciprocal benefit surrounding PPPs- and the capacity for both public and private sector accountability under such arrangements.

[176] Knoppers et al (n88); Petersen (n95); CESCR General Comment 25 (n87).

My research further seeks to contribute to an emerging subsection of CDS literature on the political economy of health data-[177] exploring the effects of data-driven research partnerships for distributive data justice- as well as advancing understanding of Big Tech's growing power and political influence. In particular, by focusing on the DeepMind-NHS case, I aim to further critical understanding of Google and its expansion into healthcare, responding to calls for closer scrutiny of the 'Googlization' of health research.[178]

The interdisciplinarity of this thesis also affords the opportunity to generate dynamic and original insight into the topic of data-driven research and the multiple disciplinary branches it spans. Firstly, I hope to demonstrate how critical political economic analysis can illuminate socio-economic rights concerns in novel ways and how an interactive dialogue between these disciplines might benefit research in the field of international human rights law. Historically, human rights approaches have avoided engaging with economic questions, leading some critics to claim that the human rights movement has either failed to challenge or even been complicit in the emergence and proliferation of the neoliberal economic order.[179] By directly addressing questions of political economy, the state-business nexus, and corporate power over human rights, my research is intended to make an early contribution to the nascent field of human rights and political economy, building upon the work of

[177] Parry & Greenhoulgh (n68); Mazzucato (n65); Birch et al (n40).
[178] Sharon 'The Googlization of health research...' (n41).
[179] David Birchall, 'Human Rights and Political Economy: Realizing Rights Within and Beyond Global Capitalism' (2021) available at SSRN < https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3780591 > (accessed 19 June 2021); Naomi Klein, 'The Shock Doctrine' (2007, Metropolitan Books); Susan Marks, 'Human rights and root causes' (2011) The Modern Law Review 74(1): 57-78; Samuel Moyn, 'Not Enough: Human Rights in an Unequal World' (2019, Harvard University Press).

those human rights scholars who advance an alternative, constructive vision of human rights as a counterforce to neoliberal inequalities.[180]

The evolution of some human rights- notably the right to privacy- have received substantial attention from the UN and human rights scholars in the context of the data economy.[181] However, the implications of this paradigm techno-economic shift for socio-economic rights like the right to health have not been explored to the same extent. By drawing on insight from CDS on the political economy of health data, I hope to demonstrate how an interdisciplinary socio-legal approach can illuminate the important implications of shifts in the technological landscape for socio-economic rights like the right to health. In doing so, I seek to contribute to a deeper understanding of so-called 'postindustrial rights violations' and the meaning of the right to health in the digital age, moving beyond the predominant focus a narrow subset of rights in this context.[182]

The ethico-legal lens of international human rights law also offers a new angle on political economic and sociological issues. Brinkerhoff and Brinkerhoff have suggested that PPPs may be a vehicle to promote good governance values like human rights;[183] by approaching the DeepMind-NHS partnership through the lens of the right to health, I hope to contribute to scholarship on the 'normative elements' of PPPs,[184] which have thus far remained marginal in discussions around the risks and benefits of PPPs. Furthermore, by framing questions of distributive justice and

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[180] Birchall (n179); Amy Kapczynski, 'The right to medicines in an age of neoliberalism' (2009) Humanity: An International Journal of Human Rights, Humanitarianism, and Development 10(1): 79-107; Philip Alston, 'The populist challenge to human rights' (2017) Journal of Human Rights Practice 9(1): 1-15.
[181] Di Iorio et al (n86); Chan et al (n86); UNGA (n81); UN OHCHR (n83).
[182] Changrok Soh and Daniel Connolly, 'New frontiers of profit and risk: The Fourth Industrial Revolution's impact on business and human rights' (2020) *New Political Economy*: 1-18.
[183] Brinkerhoff & Brinkerhoff (n39).
[184] Ibid.

accountability through the lens of socio-economic rights, my research seeks to explore the potential role of international human rights law in debates around ethical health data governance and regulation.[185]

[185] Sharon, 'The Googlization of health...' (n41); Sharon 'When digital health meets digital capitalism...' (n41).

Chapter 2: Literature Review

2.1. The Political Economy of Public-Private Partnerships in Health

2.1.1. PPPs: Background Context

The term 'public-private partnership' is widely associated with the proliferation of novel institutional arrangements between the public and private sectors beginning in the 1980s. Despite this, the question of what exactly constitutes a partnership remains subject to debate.[186] This is partly due to the challenge of encapsulating the heterogeneity of public-private partnership forms under a single definition. However, some scholars suggest that the 'politicisation' of the term public-private partnership renders it nothing more than a rhetorical device intended to conceal the covert privatisation of public services.[187]

For the purposes of this thesis, I adopt Hodge and Greve's broad definition of PPPs as "cooperative institutional arrangements between public and private sector actors".[188] This definition encompasses a wide range of different partnership arrangements, enabling me to connect previously disparate political economy analyses of public-private partnerships in health infrastructure and services, global health and pharmaceutical provision and draw out commonalities.

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[186] Graeme A. Hodge & Carsten Greve *The Logic of Public-Private Partnerships: The Enduring Interdependence of Politics and Markets* (Edward Elgar Publishing, 2019).
[187] Hodge & Greve (n39).
[188] Ibid 1.

PPPs for health infrastructure and services are rooted in the doctrine of the New Public Management (NPM) movement, a wave of public sector reforms ushered in by governments in the UK, US, Australia and New Zealand in the 1980s.[189] NPM is based on neoliberal and managerialist theories, which argue that privatization and marketization are key to reforming the lethargic and bureaucratic state.[190] In this context, PPPs were posited as mutually-beneficial arrangements with a number of benefits, such as improving public sector efficiency, providing value for money for taxpayers, facilitating innovation and sharing risks between public and private sectors.[191] Furthermore, proponents argued that introducing private sector managerial practices- including more formal monitoring and reporting mechanisms- into public sector projects could help strengthen transparency and accountability.[192] PPPs were thus championed by policymakers as an innovative tool to leverage private capital for public sector initiatives and an alternative to more traditional procurement practices or outright privatization of public services.[193]

Broadly speaking, PPPs in infrastructure and services "involve private companies in the design, financing, construction, ownership and/or operation of a public sector utility or service".[194] Though this definition covers a broad array of partnership models, the most prolific example of PPP in health infrastructure and services is PFI, which was widely instigated across the NHS from the late 1980s to the early 2000s to fund the building and servicing of NHS hospitals.[195]

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[189] Dunleavy et al (n49).
[190] Mark Bevir *Key Concepts in Governance* (Sage, 2009).
[191] Hodge (n57); Hodge & Greve (n39); Hodge & Greve (n50).
[192] Hood et al (n55).
[193] Stephen H. Linder 'Coming to Terms With the Public-Private Partnership' (1999) Am Behav Sci 43(1) 35-51; Roger Wettenhall, 'The Rhetoric and Reality of Public-Private Partnerships' (2003) Public Organ Rev 3 77-107; Hodge & Greve (n186).
[194] Akintola Akintoye et al *Public-Private Partnerships: Managing Risks and Opportunities* (John Wiley & Sons, 2008) xix.
[195] Julie Froud & Jean Shaoul 'Appraising and evaluating PFI for NHS hospitals' (2001) Financial Account Manag 17(3) 247-270.

PFIs were introduced by the Conservative government in 1992 and subsequently rebranded under the umbrella term 'public-private partnerships' by the successive Labour government in 1997.[196] The initiative promised to improve the NHS' dilapidated hospital infrastructure by delivering efficiency savings, improving health service quality, transferring risk to the private sector, and bringing private sector expertise and managerial skills to infrastructural projects.[197] PFI projects typically necessitated long-term contracts lasting 20-35 years, during which time a consortium of companies would fund, construct, operate and maintain a project in exchange for an annual payment from their public sector partner.[198]

In addition to partnerships in the provision of health infrastructure and services, PPPs have become an increasingly significant source of finance for interventions in global health. These partnerships- often referred to as GHPs- grew in popularity from the 1980s to 2000s in response to the UN's perceived inefficiency and ineffectiveness in tackling global health challenges and ensuring universal access to global public goods.[199] Furthermore, the emergence of private philanthropic foundations like the Bill and Melinda Gates Foundation represented a novel source of vast wealth and resource that innovators sought to capitalise on to address unmet needs in the global health landscape.[200]

Much like PPPs in infrastructure and financing, GHPs are diverse and heterogenous; Buse and Walt broadly categorise them into three distinct types- product development, product-based and systems or issue-based.[201] Fundamentally,

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[196] Shaoul (n59).
[197] Flinders (n55).
[198] Hood et al (n55) 42.
[199] Kent Buse & Andrew Harmer 'Power to the Partners? The politics of public-private health partnerships' (2004) Development 47(2) 49-56.
[200] Ibid.
[201] Buse & Walt (n55)

they involve collaboration between private corporations and governments, international agencies, and nongovernmental organizations.[202] High profile examples include the Global Fund to Fight AIDS, Tuberculosis and Malaria and the GAVI, The Vaccine Alliance, a multi-stakeholder collaboration intended to increase provision of and access to pharmaceuticals in developing countries.[203]

Both the Global Fund and GAVI are examples of what Buse and Walt term 'product development partnerships'; that is, PPPs initiated by the public sector and intended to incentivise the development of socially-valuable goods that would otherwise be neglected by commercial actors as their potential costs outweigh the opportunity cost of investment.[204] Commercial actors may engage in product development partnerships to receive subsidies for research, assistance in conducting clinical trials or to pursue long-term interests like financial returns or proximity to regulatory processes. Product-development partnerships are particularly favoured by the UK government; in 2018, the UK provided $230 million of funding to product development for poverty-related and neglected diseases.[205]

In addition to GHPs, the so-called 'implicit public-private partnership' in pharmaceutical R&D also facilitates the provision of medicines around the world.[206] The high costs and rates of attrition associated with the development of pharmaceuticals are significant barriers to innovation; PPP in pharmaceutical R&D is thus perceived to confront these challenges by integrating the capabilities and

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[202] Michael Reich 'Public-private partnerships for public health' (2000) Nat Med 6(6) 617-620.
[203] GAVI The Vaccine Alliance 'About our Alliance' <www.gavi.org/our-alliance/about> accessed 6 August 2020.
[204] Buse & Walt (n55).
[205] 'United Kingdom- Global health R&D' <https://donortracker.org/UK/globalhealthrd> accessed 6 August 2020.
[206] Anthony Harrison 'Getting the right medicines? Summary' (King's Fund Publications, 2003) <www.kingsfund.org.uk/sites/default/files/field/field_publication_file/getting-right-medicines-putting-public-interests-heart-health-related-research-tony-harrison-kings-fund-1-december-2003.pdf> accessed 6 August 2020.

expertise of a diverse range of stakeholders, shortening drug discovery times, reducing associated costs and improving drug success rates.[207] Pharmaceutical innovation often receives public sector support in the form of grants, subsidies or tax breaks from bodies like the US National Institutes of Health (NIH) or the Medical Research Council (MRC) in the UK; as such, the public sector is a 'cornerstone' of the pharmaceutical industry, often investing in the risky early stages of innovation.[208] Collaboration between governments and the pharmaceutical industry also extends to the procurement of medicines; for example, in the UK, the Pharmaceutical Pricing Regulation Scheme (PPRS) regulates the introduction of medicines into the NHS, seeking to ensure patients have access to the most effective medicines at the best price while supporting innovation in the pharmaceutical industry.[209] Thus, partnership between the public and private sectors is present throughout the life-cycle of pharmaceutical provision, from the research and development of medicines to their procurement in public health systems.

These PPP models are united by a common underlying philosophy: that collaboration between the public and private sectors is mutually beneficial and promotes shared risk-taking and innovation.[210] Yet partnerships across health infrastructure and services, global health and pharmaceutical provision have also been subject to common criticisms surrounding their cost-effectiveness, inequitable outcomes, and lack of accountability. Furthermore, PPPs raise fundamental questions about the nature, values and roles of the public and private sectors and

[207] Kenneth A Getz & Kenneth I Kaitin 'Open innovation: the new face of pharmaceutical research and development' (2012) Expert Rev Clin Pharmacol 5(5) 481-483.
[208] Marianna Mazzucato, Henry Lishi Li and Ara Darzi 'Is it time to nationalise the pharmaceutical industry?' (2020) BMJ 368, 1.
[209] Harrison (n206).
[210] Hodge & Greve (n39) 4.

the tension between public benefit and private profit-making.[211] Here, I review critical political economy scholarship around PPPs in health, interrogating claims surrounding the benefits of partnership models and exploring common critiques of their political and economic implications. In doing so, I seek to situate data-sharing partnerships in the broader context of a critical political economy of public-private partnership models.

2.1.2. The Question of Value

2.1.2.1. Value for Money in Health PPPs

Cost-effectiveness or value for money (VfM) are key criteria used to justify the use of PPP models in health. Mazzucato argues that this justification is based on the assumption that the private sector is inherently more efficient and innovative than the public sector, and thus better able to provide services or develop products at a cheaper price.[212] The VfM rationale was central to the establishment of healthcare PFIs in the NHS; Pollock suggests proponents of the PFI model initially claimed it could boost investment in health infrastructure without increasing public sector borrowing.[213] However, Shaoul highlights how their focus later shifted to the microeconomic case for PFI, arguing it could deliver greater VfM on the basis that the private sector is more efficient and takes on some financial risk.[214] Similarly, the

[211] Hodge & Greve (n186).
[212] Mazzucato (n39) 47.
[213] Allyson M. Pollock et al 'Private finance and "value for money" in NHS hospitals: a policy in search of a rationale?' (2002) BMJ 324(7347) 1205-1209.
[214] Shaoul (n59).

National Audit Office- the UK's independent public spending watchdog- claimed that PFI projects could improve operational efficiency, incentivising the private sector to build assets to budget and reduce long-term running costs.[215] Others hoped that VfM appraisal- which utilized a well-established methodology to compare the costs of the PFI with those of conventional public procurement- could also increase the transparency of the public procurement process.[216]

Buse and Harmer highlight how the VfM assumption is also frequently used to justify PPPs in the context of global health.[217] The first comprehensive review of the impact of GHPs on health systems- undertaken by the World Health Organisation- found that they hold the possibility of improving efficiency and assuring value for money.[218] Additionally, Lorenz argues that many GHPs themselves claim to be cost-efficient;[219] his observation is supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria's commitment to obtaining the best VfM for goods and services and GAVI's inclusion value for money as a key criterion for evaluation in its vaccine investment strategy.[220]

Furthermore, Mazzucato and Roy argue that cost-effectiveness is one of two key metrics underlying value-based pricing in the pharmaceutical sector, which has become the prevailing narrative used to justify the prices of new medicines.[221] VfM

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[215] National Audit Office 'PFI and PF2' (18th January 2018) HC718 Session 2017-2019 <www.nao.org.uk/wp-content/uploads/2018/01/PFI-and-PF2.pdf> accessed 21 September 2020.
[216] Martina Santandrea et al 'Value for money in UK healthcare public-private partnerships: A fragility perspective' (2015) Public Policy Adm 31(3) 260-279.
[217] Buse & Harmer (n199).
[218] WHO Maximizing Positive Synergies Collaborative Group, 'An assessment of interactions between global health initiatives and country health systems' (2009) Lancet 373(9681) 2137-2169.
[219] Nicolaus Lorenz 'Effectiveness of global health partnerships: will the past repeat itself?' (2007) Bull World Health Organ 85(7) 501-568.
[220] Overview' <www.theglobalfund.org/en/sourcing-management/> accessed 6 August 2020; 'Vaccine investment strategy' <www.gavi.org/our-alliance/strategy/vaccine-investment-strategy> accessed 6 August 2020.
[221] Marianna Mazzucato & Victor Roy 'Rethinking value in health innovation: from mystifications towards prescriptions' (2018) J Econ Policy Reform 22(2) 101-119.

thus appears to be a common rationale for the use of PPP governance models in health.

2.1.2.2. Appraisal

Despite the shared notion that PPPs in health deliver VfM, numerous critical scholars have highlighted the problematic nature of the appraisal procedures through which VfM is assessed. In the context of PFI, both Shaoul and Hodge and Greve have drawn attention to the ambiguity of the term 'value for money', which obscures the political choices that underpin the selection of appraisal techniques and measures it encompasses.[222] Their shared criticism refers to the fact that most PFI debt is classified as off-balance sheet and does not fall under official figures of public sector spending.[223] Thus, as Hare contends, governments are incentivised to use PFI as "a way of getting more of the investment needed without adding to the public-sector deficit or debt".[224] Pollock and Shaoul suggest that this short-term incentive obscures broader questions of long-term affordability and sustainability, resulting in an 'affordability gap' to be made up further down the line.[225] Criticisms of VfM appraisal in PFI are thus widespread among political economists.

Furthermore, value-based pricing systems- a common feature of the implicit PPP in the pharmaceutical sector- have faced criticism from Mazzucato and Roy, who argue that they obscure the impact of monopoly, financial markets, and

[222] Shaoul 'The Private Finance Initiative or the public funding of private profit?' (n48); Shaoul 'A critical financial analysis of the Private Finance Initiative: selecting a financing method or allocating economic wealth?' (n50); Hodge & Greve (n50).
[223] NAO (n215).
[224] Paul Hare 'PPP and PFI: the political economy of building public infrastructure and delivering services' (2013) Oxford Rev Econ 29(1) 95-112, 101.
[225] Pollock et al (n213); Shaoul 'The Private Finance Initiative or the public funding of private profit?' (n50).

corporate value extraction.[226] In a separate article, Mazzucato draws attention to the ways in which pharmaceutical companies utilise corporate share buy-backs to drive up the prices of drugs to disproportionate levels, enabling them to capitalise upon value-based pricing and abuse the pharmaceutical patents system.[227] Rather than representing VfM, Mazzucato and Roy contend, drug prices instead reflect "a manifestation of "what society can bear" in the face of monopoly power".[228]

2.1.2.3. The Role of the State

The VfM justification has been further challenged by some political economists on the grounds that it neglects the critical and often risky role that states play in investing in PPPs. Mazzucato's seminal text, *The Entrepreneurial State*, made a critical contribution in this area; the author uncovered how corporate wealth extraction is facilitated by a system of socialized risk and privatized reward, whereby a select group of corporate actors reap disproportionate rewards from collective- often state-funded- risk-taking in public-private innovation processes.[229] She argues for a theory of public-private innovation that more fully comprehends how value is created through a collective, cumulative and uncertain process.[230] Mazzucato's theory of the entrepreneurial state thus casts doubt on VfM claims underlying PPPs involving the development of new innovations, as the rewards are not distributed equitably between states and commercial actors.

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[226] Mazzucato & Roy (n221).
[227] Mazzucato et al (n208).
[228] Mazzucato & Roy (n221) 106.
[229] Mazzucato (n39).
[230] William Lazonick & Mariana Mazzucato 'The risk-reward nexus in the innovation-inequality relationship: who takes the risks? Who gets the rewards?' (2013) Ind Corp Change 22(4) 1093-1128.

In other articles, Mazzucato illustrates this theory at work in the pharmaceutical sector. In a co-authored article with Roy, the authors suggest that lack of appreciation of the public sector's contribution to pharmaceutical innovation processes results in governments 'paying twice'; once for the research underpinning the development of pharmaceutical products and again to procure these products at expensive prices.[231]

Building on Mazzucato's theory, other scholars have highlighted the neglected role of the state in GHPs. McGoey reveals how government grants and subsidies play a vital role in financing medical innovations in GHPs, which the private sector capitalises upon at the expense of governments' ability to generate revenue or determine the cost-effectiveness of projects.[232] In this light, the author argues, claims about GHP's VfM are spurious.

2.1.2.4. Financial metrics vs. public interests

Another group of critical scholars argue that the predominant focus on the financial metrics of PPPs- like VfM- can overshadow consideration of broader public interests and social value. Boardman and Vining suggest that the criteria used to justify the use of PPPs- such as VfM and 'off-budget'- are not necessarily aligned with the public interest and could have a deleterious effect on social value.[233] Richter similarly argues for the need to centralise questions of public interest in PPPs; this requires "much more critical policy reflection where increased interactions between

[231] Mazzucato & Roy (n221).
[232] McGoey (n51).
[233] Boardman & Vining (n52).

public and business actors is likely to positively and negatively impact on the achievement of health for all".[234]

Brinkerhoff and Brinkerhoff make a critical contribution in this area;[235] moving beyond scrutiny of the financial aspects of PPPs, the authors assess the extent to which partnerships deliver public benefits and advance good governance values like human rights. They highlight how, in practice, many PPPs do not achieve their purported benefits due to poor implementation, skewed incentives, or the production of unintended consequences like reduced long-term government capacity. The authors also argue that private sector benefits, while critical to incentivise corporate involvement in PPPs, are not necessarily aligned with social goals; for this reason, achieving the mutual benefits of partnerships requires an appropriate balance between public and private interests.[236]

Brinkerhoff and Brinkerhoff shine a light on the thus far underappreciated 'normative component' of PPPs; that is, their potential as a mechanism for advancing good governance norms like basic freedoms and human rights. Where such principles are enacted in PPPs, they suggest, "inclusion, equity, transparency, accountability and ethical behaviours become integral to the partnership functions".[237] However, they argue that- in practice- the extent to which partnerships advance these goals varies widely.[238] Together, this group of scholars draw attention to the need for claims about the financial benefits of PPP to be situated in the broader context of societal objectives and the public interest.

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[234] Richter (n52) 47.
[235] Brinkerhoff & Brinkerhoff (n39).
[236] Ibid.
[237] Ibid 12.
[238] Ibid.

2.1.3. Health equity

Beyond VfM claims, political economists highlight how PPPs in health often purport to target areas of critical need in health systems, with a view to improving the health of the most vulnerable. PFI projects focused on NHS hospitals requiring urgent infrastructural investment, which NHS trusts were unable to finance upfront. Similarly, Ruckert and Labonte observe that GHPs often have equity objectives;[239] Brinkerhoff and Brinkerhoff concur, arguing that many global health research consortia explicitly state their commitment to improving equity while those that do not may implicitly do so by focusing on developing treatments for conditions more common in low- and middle-income countries.[240] Equity is also a vital consideration in public-private collaboration for pharmaceutical provision; Gardner et al contend that facilitating equitable access to medicines is the fundamental goal of state involvement in this area.[241] These scholars' contentions are supported by Brinkerhoff and Brinkerhoff's observation that equity is often part of the explicit rationales of PPPs in health.[242]

Despite the prevalence of equity as a justification for PPPs, some political economists suggest partnerships may have the opposite effect in practice. Clark and McGoey argue that GHPs are often directed towards the most profitable causes for the private sector, which do not necessarily align with areas of greatest health need.[243] In a similar vein, Ruckert and Labonte suggest equity objectives in GHPs

[239] Ruckert & Labonté (n54).
[240] Brinkerhoff & Brinkerhoff (n39).
[241] Charles A. Gardner et al 'Technological and Social Innovation: A Unifying Paradigm for Global Health' (2007) Health Aff 26(4) 1052-1061.
[242] Brinkerhoff & Brinkerhoff (n39) 9.
[243] Clark & McGoey (n54).

may lack substance, as 'pro-poor' approaches are not necessarily incorporated into operational practices or monitoring activities.[244] PPPs for pharmaceutical innovation face similar criticisms, as McGoey accuses pharmaceutical companies of prioritising profit-making over health equity by focusing on the development of 'blockbuster' drugs at the expense of commercially unappealing medicines that serve the needs of the poorest and most vulnerable.[245]

Other scholars highlight how PPPs can undermine health equity through neglect of the broader health systems in which they operate. Shaoul argues that PFI projects may undermine sound decision-making at the national level and destabilise the health system, as the spiralling costs of PFI debts are ultimately met by the taxpayer.[246] GHPs have faced similar critiques; Ruckert and Labonte highlight that GHPs are often narrow and targeted interventions that rarely address health systems strengthening or account for their wider implications.[247] Pratt and Loff share their concern, highlighting how the regulation of research in global health is focused around commercially-appealing health needs that require high-tech, profitable solutions; this diverts funding from existing interventions and broader health systems strengthening.[248] This body of scholarship thus suggests that, despite the inclusion of equity as a key objective in many PPPs, these models may prioritise corporate profit-making over public health needs or weaken the broader health systems in which they operate, leading to inequitable outcomes in practice.

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[244] Ruckert & Labonté (n54).
[245] Linsey McGoey et al 'The global health complex' (2011) BioSocieties 6 1-9; Mazzucato et al (n208).
[246] Shaoul 'A critical financial analysis of the Private Finance Initiative: selecting a financing method or allocating economic wealth?' (n50).
[247] Ruckert & Labonté (n54).
[248] Pratt & Loff (n54).

2.1.4. Transparency and Accountability

Some political economists argue that transparency and accountability are critical to the effectiveness and legitimacy of PPPs in health. For Hood et al, transparency in PPPs is vital to both public and private sectors, maintaining trust in the integrity and value of public investments on the one hand while giving confidence to capital markets on the other.[249] PFI agreements, the authors argue, emerged in the context of a public rhetoric purporting to make government more open and accountable, of which target setting, monitoring and performance review were increasingly importance features. Transparency and accountability are also purported to be important features of GHPs; Reich argues that transparency allows learning and facilitates accountability, which assures public interest goals are achieved, improves organizational performance and contributes to public trust and democracy.[250] Reich's view is supported by Brinkerhoff and Brinkerhoff's observation that accountability is often used as an explicit justification for PPPs.[251]

2.1.4.1. Complexity of PPP structures

Despite claims to transparency and accountability in PPPs in health, these collaborations are often characterised by complex financial and organisational structures, which some suggest are problematic for accountability. Flinders emphasises the hybridity of PPPs, highlighting how allocating responsibility for failure is a challenging task.[252] Hodge similarly describes a changing of the guardian in PPPs from a simplistic accountability regime to a 'complex network of

[249] Hood et al (n55).
[250] Reich (n59).
[251] Brinkerhoff & Brinkerhoff (n39).
[252] Flinders (n55).

guardians'.[253] In support of Flinders and Hodge's view, Hood et al argue that this institutional complexity erodes "traditional Weberian notions of bureaucratic control and accountability".[254]

By comparison, Buse and Walt are more specific in their criticism, pointing to the autonomy of individual actors in GHPs as the compounding factor that can undermine accountability.[255] Taken together, however, the views of scholars who highlight the complexity of PPP structures imply that this fundamental feature of PPPs presents a challenge to accountability.

2.1.4.2. Opacity

Lack of public sector transparency is a further criticism levelled at PPPs in health. Hodge and Greve contend that PPPs in health infrastructure have provided limited opportunities for meaningful transparency.[256] Their contention is supported by evidence from PFI; Shaoul highlight how finding even basic data about PFI projects- including their number, size and costs- is hugely challenging.[257] Hood et al argue that this lack of public sector transparency in PFI leads to a 'democratic accountability deficit'.[258]

The private sector's use of commercial confidentiality laws has also been identified by some as perpetuating the opacity around PPPs in health. Hood et al argue that commercial actors are able to evade transparency through issues around appraisal and accounting, inadequate corporate reporting disclosure, and corporate

[253] Hodge (n57).
[254] Hood et al (n55) 44.
[255] Buse & Walt (n55).
[256] Hodge & Greve (n39).
[257] Shaoul 'The Private Finance Initiative or the public funding of private profit?'(n50) 194.
[258] Hood et al (n55).

confidentiality agreements.[259] Their concerns echo those of Flinders, who criticises the overuse of commercial confidentiality laws to prevent the disclosure of information that may demonstrate VfM and dispel public mistrust.[260]

Beyond PFI, commercial confidentiality has also been criticised in GHPs; McGoey argues that private philanthropic foundations are not subject to the same disclosure requirements as the public sector, creating opacity around the cost-effectiveness of GHPs and the allocation of funding towards corporate interests.[261] Together, these scholars cast doubt on the notion that PPPs in health necessarily facilitate transparency, instead demonstrating how lack of public sector transparency and commercial actors' use of commercial confidentiality laws may in fact generate opacity.

2.1.4.3. Lack of oversight and accountability mechanisms

Lack of oversight and mechanisms to enforce accountability has been identified as a further barrier to transparency and accountability in PPPs in health. Hood et al criticise PFI contracts for lacking "the normal welter of oversight, regulatory, and scrutiny mechanisms that other public services face".[262] Brown's view suggests GHPs may be similarly limited; the author highlights how the lack of global norms or frameworks to guide the regulation of GHPs results in the establishment of ad-hoc, largely unregulated partnerships.[263] In a more nuanced observation, Hodge argues that- while managerial accountability may have improved

[259] Hood et al (n55).
[260] Flinders (n55).
[261] McGoey (n56).
[262] Hood et al (n55).
[263] Brown (n57).

under the PPP paradigm- this has been at the expense of public accountability mechanisms like parliamentary control, quasi-judicial mechanisms, and transparency.[264] Thus, despite claims to improved accountability- some of which, Hodge suggests, may be legitimate- PPPs in health may lack effective regulatory oversight and public accountability mechanisms.

2.1.3.5. The covert expansion of private power

Other critics have drawn attention to the ways in which PPPs in health facilitate the covert expansion of private interests and power. Some political economists argue that PPPs can fall victim to corporate bias and regulatory capture; Shaoul highlights how the Treasury's project's division- which oversaw PFI projects- was itself reconstituted as a PPP called Partnerships UK, whose structure, ownership and control was dominated by private interests with a vested interest in expanding PFI.[265]

GHPs have faced similar accusations of corporate bias. Buse and Harmer have written extensively about the relationship between GHPs and public-private power relations; like Shaoul, they highlight how board compositions- alongside membership criteria and hosting arrangements- facilitate the expansion of private interests into the public domain, allowing corporations influence over the establishment of norms and standards in global health.[266] They thus argue that

[264] Hodge (n57) 8.
[265] Shaoul 'The Private Finance Initiative or the public funding of private profit?' (n50) 193.
[266] Buse & Harmer (n199).

GHPs are an avenue through which the private sector attempts to exert power in intergovernmental forums, expand markets and enhance corporate citizenship.[267]

Like Shaoul and Buse and Harmer, John Abraham has drawn attention to the problem of regulatory capture, but his focus is the pharmaceutical sector. The author suggests that corporate bias permeates policy development, implementation and interpretation in this context, operating via a 'revolving door' between regulatory agencies and industry and the use of corporate confidentiality legislation.[268]

Beyond criticisms levelled at corporate bias and regulatory capture, other scholars suggest that PPPs in health afford the private sector significant influence over public health research agendas. Both Faubion et al and Reich draw attention to corporate-funded philanthropic foundations' manipulation of research agendas through their financial and political might;[269] in this context, Faubion et al argue, foundations have arguably become 'de-facto agenda-setters' in global health.[270] Clark and McGoey similarly heed warning about the role of corporate-funded philanthropic foundations in setting global health research agendas, using the term 'philanthrocapitalist' to refer to the entrepreneurs who run such GHPs and gain influence and moral legitimacy from their public image as efficient and innovative 'technological wizards'.[271]

Another set of scholars argue that the obfuscation of the public-private boundary in PPPs in health is a key enabling factor in the expansion of private power. Ruckert and Labonte suggest that GHPs are particularly problematic in

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[267] Kent Buse & Gill Walt, 'Globalisation and multilateral public-private health partnerships: issues for health policy' in Kelley Lee, Kent Buse & Suzanne Fustukian (eds) *Health Policy in a Globalising World* (Cambridge University Press, 2002) 41- 62.
[268] John Abraham 'The pharmaceutical industry as a political player' (2002) Lancet 360(9344) 1498-1502; John Abraham 'Partial Progress: Governing the Pharmaceutical Industry and the NHS, 1948-2008' (2009) J Health Pol Pol'y & L 34(6) 931- 978.
[269] Faubion et al (n59); Reich (n202).
[270] Faubion et al (n59) 209.
[271] Clark & McGoey (n54).

obscuring the divide between public and private, thus rearranging the boundaries of the public and private spheres in an effort to further entrench private interests.[272] Richter's criticism particularly targets the use of the term 'partner', which- she argues- obscures key distinctions between the roles and obligations of different actors in GHPs.[273] Richter describes this as "one of the most substantive losses of the partnership paradigm"[274].

Together, these scholars' arguments suggest- as opposed to promoting greater corporate accountability- PPPs in health instead enable commercial actors to expand their power and influence through multiple avenues, including corporate bias and regulatory capture, control over research agendas, and the blurring of the public-private distinction.

2.1.4. Conclusion

This section has reviewed critical literature on the political economy of PPPs in health. Collating critical scholarship on PPPs across different domains in health, it reviewed the literature surrounding three common claims that are made about them; that they provide value for money, improve health equity and facilitate accountability. In doing so, it revealed that common challenges and limitations underlie PPPs in health, illustrating how novel applications of the partnership model "may not be all that new" after all.[275] In this respect, this body of scholarship draws attention to the so-called 'politicisation' of the partnership paradigm, which has evolved over space

[272] Ruckert & Labonté (n54).
[273] Richter (n52) 46.
[274] Richter (n52) 46.
[275] Hodge & Greve (n39) 16.

and time to meet the political need of the moment.[276] Furthermore, it reveals that- despite the rhetoric of mutual benefit surrounding PPPs- they often necessitate trade-offs in practice.

As well as these common underlying themes, reviewing this body of literature has also shed light on areas that require further scholarly investigation. As Brinkerhoff and Brinkerhoff highlight, the broader impacts of PPPs on public interests and good governance values like human rights have received little attention, resulting in limited knowledge of the normative dimensions of this form of governance.[277] Furthermore, there is little in-depth case study analysis of specific examples of PPPs in practice, meaning there is limited understanding of the impact of context on the political economy of PPP. In addition, the PPP model is used in a broader range of contexts in health than those addressed in the literature here; there is therefore a need to turn attention to novel iterations of the PPP model in health to deepen our understanding of its continued 'politicisation' today.

The focus of my study- the DeepMind-NHS partnership- is one such novel iteration. Much like public-private collaboration in the pharmaceutical and global health sectors, data-driven research partnerships like DeepMind-NHS are purported to promote mutually-beneficial health innovation. However, the DeepMind-NHS partnership is also novel and distinct in that it relies on commercial access to public sector data. The emergence of the so-called 'data economy' underlying the revolution in data-driven and automated technological innovation is a paradigm shift with significant implications for the relationship between public and private sectors and the dynamics of innovation. As such, the following section reviews scholarship

[276] Hodge & Greve (n186).
[277] Brinkerhoff & Brinkerhoff (n39).

from the sociological subdiscipline critical data studies, with a view to situating the DeepMind-NHS partnership in the broader political economy of health data.

2.2. The Political Economy of Health Data

2.2.1. Introduction

Since its inception in 2014, CDS has emerged as a distinct area of sociological enquiry concerned with "the unique cultural, ethical, and critical challenges posed by Big Data".[278] In contrast to empirical approaches- in which data are "presented as new and innovative, emerging ahistorically to revolutionize modern life"- [279] CDS scholars are concerned with 'data assemblages'; a term coined by early contributors Kitchin and Lauriault to describe "the technological, political, social and economic apparatuses and elements that constitutes and frames the generation, circulation and deployment of data".[280]

One emerging branch of CDS focuses specifically on the political economy of data, a reflection of growing scholarly awareness of data as a valuable asset in the knowledge economy.[281] Health data, Parry and Greenhough argue, warrants particular attention in this context, as they "inhabit two identities simultaneously: the first as highly personal and private data, the other as corporately owned property".[282]

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[278] Andrew Iliadis & Federica Russo 'Critical data studies: an introduction' (2016) Big Data Soc 3(2) 2053951716674238, 1.
[279] Craig M. Dalton & Jim Thatcher 'Inflated Granularity: Spatial 'big data' and geodemographics' (2015) Big Data Soc 2(2) 2053951715601144, 1.
[280] Kitchin & Lauriault (n62) 1.
[281] Kitchin & Lauriault (n62); Birch (n62); Prainsack (n40).
[282] Parry & Greenhoulgh (n68) 14.

The commercialisation of health data has thus garnered attention in CDS from those who question who will benefit from these developments, how, and at what cost.[283] Driving this shift are technology giants like Google who seek to access health data for the development of algorithmic technologies. As Big Tech expand into healthcare markets, critical scholars have voiced concerns about their power, influence and lack of accountability.

This section reviews CDS literature on the emerging political economy of health data. It begins by exploring issues of resource distribution or distributive data justice; that is, "the concern for who gets what as a result of data systems".[284] In particular, it considers how Big Tech's business model facilitates corporate wealth extraction and monopoly, its implications for health equity and how concepts of value and public benefits are utilised in this context. The subsequent section explores literature on the power and politics of Big Tech, including the opacity surrounding the platform monopolies, the risks posed by their political influence, the trend towards ethical capitalism in data-driven health innovation, Big Tech's lack of democratic accountability, and the particular role of Google. Together, this body of scholarship reveals how "digital data is becoming an increasingly important element in the production of knowledge, wealth, and power".[285]

2.2.2. The distributive effects of data-driven health innovation

[283] Prainsack (n40).
[284] Richard Heeks & Satyarupa Shekhar 'Datafication, development and marginalised urban communities: an applied data justice framework' (2019) Inf Commun Soc, 22(7) 992-1011, 1006.
[285] Prainsack (n40) 1.

2.2.2.1. Big Tech's business model: monopoly and wealth extraction

CDS scholars have drawn attention to Big Tech's business model and the ways in which it facilitates corporate wealth extraction and monopoly. Mazzucato describes how the effects of modern digital networks and the characteristics of digital innovation tend towards monopoly, enabling just a few market leaders to extract value on an unprecedented scale.[286] In particular, she highlights how dynamic increasing returns to scale and network externalities have facilitated the rapid expansion of Big Tech and their self-perpetuating market dominance, "placing an enormous concentration of market power in the hands of a few firms".[287] As a result, the author argues, "companies like Google are de facto monopolies".[288]

Mazzucato further suggests these effects are the product of the two-sided markets in which Big Tech operate, which results in an increase in the number of search engine or social network users boosting the company's appeal to advertisers and thus its profitability. As a result, rather than viewing Google as providing user services for free, "it is users who provide Google with necessary inputs for the production process: their looks on ads and, most importantly, their personal data".[289] Shoshana Zuboff describes this business model as a new economic paradigm that she labels 'surveillance capitalism',[290] "a new economic order that claims human experience as free raw material for hidden commercial practices of extraction, prediction, and sales".[291] Like Mazzucato, Zuboff highlights how surveillance capitalism is 'parasitic'- in that it feeds on human experience- rendering digital

[286] Mazzucato (n65).
[287] Ibid 218.
[288] Ibid.
[289] Ibid 216.
[290] Zuboff (n63).
[291] Ibid.

connection through social networks "a means to others' commercial ends".[292] Evgeny Morozov has also been a vocal critic of the platform monopolies' business models, which he terms 'data extractivism';[293] that is, the notion that "users are valuable stocks of data; technology companies, in turn, design clever ways to have us part with that data — or at least share it with them".[294]

Birch et al describe this model as 'data rentiership', "the pursuit of innovation strategies designed to capture or extract value through ownership and control of data as an asset".[295] The authors draw attention to the 'innovation-finance nexus'- the increasingly blurred boundary between technoscientific innovation and finance- which is "characterized by the deliberate pursuit of economic rent extraction or regulatory rent-seeking through the extension of IP rights, monopoly control, network effects, and/or reconfiguration of techno-economic processes".[296] Big Tech's business model, the authors argue, is fundamentally rooted in this innovation-finance nexus, such that "innovation is driven by the search for ways to create, extend, and reinforce the ownership and control of assets (i.e. rentiership) – especially personal data – while acquiring competitors who threaten monopoly positions or lobbying governments who threaten to introduce regulations".[297] Thus, they contend, the 'assetization' of data- the transformation of personal data into a financial entity- has become the predominant logic driving scientific research and development, at the expense of the development of useful technologies and services that deliver societal benefit.

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[292] Ibid.
[293] Morozov (n63); Evgeny Morozov 'Digital Intermediation of Everything: At The Intersection of Politics, Technology and Finance' (2018) 4th Council of Europe Platform Exchange on Culture and Digitisation, Karlsruhe <https://rm.coe.int/digital-intermediation-of-everything-at-the-intersection-of-politics-t/168075baba> accessed 7 August 2020.
[294] Morozov (n293) 2.
[295] Birch et al (n40) 3.
[296] Ibid 4.
[297] Ibid 7.

2.2.2.2. The inequitable effects of public-private data-driven health research

In the context of health research, the transformation of health data into a commercial asset generates novel power asymmetries based on access to data and the technologies it is used to develop. Parry and Greenhough describe the case of Myriad Genetics, a private molecular diagnostics company in the US that was granted IP rights over the BRCA-1 and BRCA-2 genes linked to breast cancer. By creating a monopoly over diagnostic testing kits, the company was able to raise prices, excluding many of the women involved in the original research to isolate BRCA genes from accessing the testing kits. Celera Genomics provides a further example; the company capitalized on the publicly-funded Human Genome Project to develop a draft human genome, later restricting access to the sequences to paying customers only despite promises to the contrary.[298]

These cases highlight how the 'assetization' of health data can simultaneously enrich corporate actors while restricting public access to the technologies it is used to develop. They exemplify how the public ends up 'paying twice' for health technologies[299]; once through the dispossession of their data and again for access to the innovations it yields. Parry and Greenhough suggest this is particularly problematic for marginalized communities, who often have the greatest need for health improvements but remain least able and likely to benefit from them.[300] This use of health data to generate corporate profits as opposed to serving the common

[298] Parry & Greenhoulgh (n68).
[299] Ebeling (n72); Mazzucato & Roy (n221).
[300] Parry & Greenhoulgh (n68).

good, Mazzucato argues, “produces a new form of inequality- the skewed access to the profits generated from big data”.[301]

2.2.2.3. Value and benefits in public-private data-driven health research: profits vs. public goods

The ‘assetization’ of health data and its inequitable effects thus raise quandaries around the value and benefits derived from health data. Critical data scholars have highlighted the lack of clarity around the meaning of these terms in this context; Parry and Greenhough stress the complexity of value appraisal in the context of health data.[302] Furthermore, while the notion of benefits was originally conceptualized as economic profits, the authors argue, it has now evolved to include public goods like improved testing, treatment, research and databases.

Through deliberative workshops with members of the public, Aitken et al revealed that the public were sceptical as to whether appropriate mechanisms were in place to realise public benefits in data-driven health research.[303] Their study further highlighted public opinion that commercial and political interests impede the benefits of health research. This reflects the contentions of Blasimme et al, who argue that the involvement of commercial actors in data-driven health research necessitates a trade-off between the economic value of health data and its public value as a scientific resource. They argue for trustworthiness, openness and

[301] Mazzucato (n65) 221.
[302] Parry & Greenhoulgh (n68).
[303] Aitken et al (n69).

evidence as the basis for balancing the different interests at stake and recognise that all stakeholders have some legitimate interests.[304]

Sharon explores these trade-offs in the context of public-private data-driven health research involving Big Tech.[305] The author identifies a diverse range of moral repertoires or conceptions of the 'common good'- termed the civic, market, industrial, project and vital narratives- which reflect a range of different motives for stakeholder engagement in data-driven research. Sharon concludes that acknowledging this 'panopoly of moral orientations' is essential to understanding the trade-offs involved in data-driven research initiatives and to ensuring that civic values are embedded in future governance solutions and calls for closer consideration of how these different repertoires play out in legislation and policymaking around data-driven technologies in health.[306]

2.2.3. The power and politics of Big Tech

2.2.3.1. The 'one-way mirror'

Some critical data scholars have denounced the secrecy surrounding the operations of the platform monopolies. In *The Black Box* Society, Pasquale draws attention to the 'one-way mirror' that enables tech corporations to simultaneously collect increasing amounts of data on citizens while shrouding their own actions in secrecy through "nondisclosure agreements, "proprietary methods," and gag

[304] Blasimme et al (n70).
[305] Sharon "When digital health meets digital capitalism..." (n41).
[306] Ibid.

rules".[307] Pasquale claims that, despite hopes that the Internet would bring about an era of openness and transparency, technology companies have "deployed strategies of obfuscation and secrecy to consolidate power and wealth".[308]

However, the author suggests that transparency alone is not a panacea, as it may conversely provoke complexity that continues to obscure corporate misconduct.[309] Prainsack similarly highlights the need to avoid conflating transparency with accountability, suggesting this would obscure important nuances regarding different types of transparency and the role of inclusiveness in decision-making.[310]

2.2.3.2. Political influence and regulatory capture

Critical scholars have also voiced concerns about political influence and the risks of regulatory capture from Big Tech. Ebeling condemns political rent-seeking- where "private organizations focus on lobbying government for policy and legislative changes, rather than on their internal research and development strategies"- [311] in her analysis of US health data protection regulation.[312] She argues that corporate bias has shaped data protection legislation in favour of the interests of the private sector, highlighting how corporations benefit from a "vantage point of socio-political power" in which decision-making about health data occurs in private.[313] This

[307] Pasquale (n71) 3.
[308] Ibid 14.
[309] Ibid.
[310] Prainsack (n73).
[311] Birch (n62) 12.
[312] Ebeling (n72).
[313] Ibid 386.

supports Prainsack's view that the tech giants have become key political players in the health domain.[314]

Their influence, however, extends far beyond health alone; Nemitz illustrates how the tech giants engage in political rent-seeking around AI regulation.[315] The author argues that technology companies have evaded responsibility in the field of AI through their influence in both the development and application of the law, stressing the need for transparency around potential conflicts of interest in the development of AI regulation.

Cath echoes his calls for closer scrutiny of industry efforts to participate in or lobby for AI regulation; like Nemitz, she highlights how claims about the enigmatic nature of technologies like AI are often used to rationalize private sector involvement in regulatory efforts.[316] The author further draws attention to the risk of regulatory capture from corporate interests in the governance of AI, pointing to the European Commission High-Level Expert Group of AI as an example; half the group's members are from industry, compared to far fewer from academia and civil society. In order to counter their political influence, Cath highlights the need to scrutinize who sets the agenda for AI governance, what logic is realized as a result, and who benefits from it.[317]

2.2.3.4. 'Ethical' capitalism in data-driven health innovation

[314] Prainsack (n72).
[315] Nemitz (n72).
[316] Ibid; Cath (n72).
[317] Cath (n72).

As Big Tech expand into new markets, they face mounting pressure to demonstrate how their own objectives are aligned with public interest goals like improving health and wellbeing.[318] In *Personalized Medicine*, Prainsack explores the complexities of this movement- which she terms 'health-data entrepreneurism'- arguing it is characterised by an increasingly symbiotic relationship between profit orientation and idealist activism. Drawing on the example of online platform PatientsLikeMe, she demonstrates how data-driven health initiatives can defy simplistic dichotomies, instead representing "a multi-layered cluster of financial, political, and societal interests that do not merely coexist but that mutually reinforce each other".[319] However, Prainsack also highlights users' lack of autonomy in decision-making on the platform, thus drawing attention to the potential pitfalls of the conflation of public and private interests.[320]

Sharon also highlights the need to reconsider the distinction between profit-making and public benefit in discussions around data-driven health research, arguing that such initiatives are more accurately characterised by "a plurality of orders of worth and conceptualizations of the common good".[321] Referring explicitly to DeepMind, the author highlights how the company's co-founder, Mustafa Suleyman, expresses sentiments that invoke both market and civic moral repertoires, demonstrating that "'doing good' is becoming an inalienable- not an additional-dimension of corporate activity".[322]

This form of 'ethical capitalism', Prainsack argues, often manifests in CSR initiatives or hybrid governance models like public-private partnerships, which claim

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[318] Prainsack (n73).
[319] Ibid 109.
[320] Ibid.
[321] Sharon 'When digital health meets digital capitalism, how many common goods are at stake?' (n41) 1
[322] Ibid 4.

to fulfil both profit and non-profit objectives.[323] CSR efforts in the area of data-driven health technology- particularly in the emerging field of AI- abound; in 2019, Mittelstadt counted at least 84 public-private initiatives developing principles and values to guide the development of AI.[324] Though there is some global convergence around principles for ethical AI,[325] such initiatives have been criticised for lacking common aims, methods for practical application, and robust professional and legal accountability mechanisms.[326] Cath has highlighted the need to assess the aims, impact and process of ethical principles and remain critical of their broader impacts, like their potential to legitimize private-sector led norm development.[327] Nemitz suggests that such efforts are "effectively delaying the debate and work on law for AI",[328] thus cutting out the democratic process, and are ineffectual in addressing the many conflicts of interests around the development and deployment of AI that exist between corporations and the general public.[329] Arogyaswamy also points to the limited effectiveness of self-regulatory efforts, which "can quickly be overcome by the sheer magnitude of screening required, the demands of shareholders for growth and profits, acquiescent corporate cultures, and sheer hubris".[330] Vaidhyanathan similarly describes CSR as 'toothless' in the face of shareholder interests.[331]

Critical scholarship of 'ethical' capitalism in data-driven health innovation thus simultaneously acknowledges the growing entanglement of profit and not-for-profit

[323] Prainsack (n73).
[324] Brent Mittelstadt 'Principles alone cannot guarantee ethical AI' (2019) Nat Mach Intell 1 501-507.
[325] Ibid; Anna Jobin et al 'The global landscape of AI ethics guidelines' (2019) Nat Mach Intell 1(9) 389-399.
[326] Mittelstadt (n324).
[327] Cath (n72).
[328] Nemitz (n72) 7.
[329] Ibid.
[330] Arogyaswamy (n73).
[331] Vaidhyanathan (n73) 43.

incentives while remaining sceptical about the intent and efficacy of CSR efforts in light of commercial pressures.

2.2.3.5. Big Tech: beyond democratic control

The movement towards 'ethical capitalism' must also be considered in the context of Big Tech's accumulation of knowledge and power, which renders them increasingly beyond democratic control. These companies have variously been described in the literature as 'Big Other' and 'iLevithian',[332] terms indicative of their omniscient powers. Zuboff and Prainsack have drawn attention to the ways in which the platform monopolies' excessive practices of data collection enable them to exert control over populations.[333] Thus, despite the emancipatory rhetoric surrounding new technologies, [334] these may simultaneously function as instruments of discipline and control.[335] This reaffirms Zuboff's argument that the economic imperatives that drive surveillance capitalism "disregard social norms and nullify the elemental rights associated with individual autonomy that are essential to the very possibility of a democratic society".[336]

Furthermore, some scholars highlight how efforts to regulate Big Tech have sometimes proven ineffectual. In their critique of Big Tech from the standpoint of societal sustainability, Arogyaswamy suggests there are numerous, constantly evolving barriers to effectively regulating Big Tech; as such, these companies may

[332] Zuboff (n63); Prainsack (n69) 2.
[333] Zuboff (n63); Prainsack (n69).
[334] Wearables are one such example. See Deborah Lupton *The quantified self* (John Wiley & Sons, 2016); Tamar Sharon 'Self-tracking for health and the Quantified Self: Articulating Autonomy, Solidarity, and Authenticity in an Age of Personalized Healthcare' (2017) Philos Technol 30 93-121.
[335] Ibid.
[336] Zuboff (n63) chap 1 sec III.

simply be too big to regulate and "regulation may do little more than slow down the damage to society, particularly since societal values and political preferences vary internationally."[337] This supports Prainsack's view that Big Tech have "become de facto market regulators against whom public and civil society actors are powerless even when faced with stark ethical misconduct".[338]

2.2.3.6. Google

Google has drawn particular attention from CDS scholars. In *The Googlization of Everything*, Siva Vaidhyanathan highlights how the company has capitalised on public failures to step into public sector roles, generating public goodwill and an image of corporate responsibility. This apparent benevolence, Vaidhyanathan argues, obscures the fact that Google is a publicly traded company obliged to act in the interests of its shareholders. Furthermore, in reality, Google's monopoly was built on public resources; the company's original search algorithm, for example, received substantial public subsidy.[339] In order to pursue global civic responsibility and the public good, the author contends, we must dismantle the perception of Google as a 'force for good' and scrutinise it as a commercial actor.[340]

Google's power and lack of accountability is also cause for concern; Zuboff highlights Google's role as a pioneer of surveillance capitalism, which has enabled it to enjoy "extraordinary new asymmetries of knowledge and power, unprecedented in the human story".[341] Vaidhyanathan suggests this has enabled Google to quash

[337] Arogyaswamy (n73).
[338] Prainsack (n74) 9.
[339] Mazzucato (n39) 19.
[340] Vaidhyanathan (n73).
[341] Zuboff (n63).

competition.[342] The author further argues that Google operates in a 'black box', in which "it knows a tremendous about us, and we know far too little about it".[343] This supports Prainsack's argument that Google is "not being subject to democratic control and public accountability in the same manner as public actors".[344]

Google's expansion into healthcare markets is further cause for concern. Tamar Sharon explores how the company's foray into health research generates novel power asymmetries between commercial actors, public health institutions and patients.[345] The author draws attention to the possibility of tech corporations like Google emerging as "mediators, gatekeepers and proprietors" of health datasets, which risks them becoming 'quasi-monopolies' able to raise prices, restrict access and reshape research agendas.[346] Sharon concludes that the 'Googlization of health research' should be closely examined and encourages further efforts to ensure its ethical governance.[347]

2.2.4. Conclusion

This section reviewed literature from critical data studies on the emerging political economy of health data, particularly around the distributive effects of data-driven research in health and the power and politics of Big Tech. It revealed how the political economy of health data is reconfiguring the public-private nexus, such that the traditional public-private dichotomy does not accurately reflect the complexity of

[342] Vaidhyanathan (n73).
[343] Ibid 9.
[344] Prainsack (n69) 127.
[345] Sharon 'The Googlization of health research...' (n41).
[346] Ibid 569.
[347] Ibid.

today's healthcare system;[348] instead, 'hybrid' initiatives like public-private partnerships and corporate responsibility programmes are redefining the relationships between public benefit and private profit-making.[349] Furthermore, this body of literature highlights the critical importance of collective issues like resource allocation and structural power in the health data economy[350], emphasising the need for research that moves beyond an individualistic, privacy-centric lens and contributing to broader debates around data justice and politics in CDS.[351]

The political economy of health data gives rise to normative issues and regulatory challenges with significant ramifications for the normative underpinnings and legal framework of international human rights law. Thus, the following section explores the human rights implications of commercial data-driven health research, with a view to situating the DeepMind-NHS partnership in the context of the human rights scholarship on health data misuse, commercialization and profiteering.

2.3. The Human Rights Implications of Commercial Data-Driven Health Research

2.3.1. Introduction

[348] Prainsack (n69); Sharon 'When digital health meets digital capitalism...' (n41).
[349] Sharon 'When digital health meets digital capitalism...' (n41); Prainsack (n40).
[350] Prainsack (n72).
[351] Andrejevic (n80); Prainsack (n69); Prainsack (n72). For data justice, see also Linnet Taylor 'What is data justice? The case for connecting digital rights and freedoms globally' (2017) Big Data Soc 4(2) 2053951717736335; Lina Dencik et al Towards Data Justice: Bridging anti-surveillance and social justice activism', in Evelyn Ruppert, Engin Isin, & Didier Bigo (eds) *Data politics* (Routledge, 2019) 167-186.

Today, there is widespread acknowledgement that the development and implementation of new data-driven technologies has significant ramifications for human rights; this has been recognised by human rights organisations at all levels and by scholarship from a growing number of human rights institutes and organisations.[352] Many of these efforts have focused on the implementation of new data-driven technologies like AI,[353] which are set to profoundly impact a wide range of human rights. However, some human rights scholars- particularly advocates of civil and political rights and the right to science- have turned their attention to the risks associated with the research and development of data-driven technologies.

In healthcare, data-driven research increasingly involves powerful technology companies, which has generated concerns about the misuse of health data among civil and political rights scholars. Data misuse is, however, just one concern associated with commercial actors in data-driven health research; health data commercialization and profiteering also pose risks to human rights, implicating a broader range of rights than health data misuse alone.[354] In particular, the right to science framework- which deals directly with pertinent issues like IP- has been the focus of economic, social and cultural rights scholarship in this area.[355]

This section reviews institutional and scholarly responses in human rights to commercial data-driven health research, focusing on the implications of health data misuse for the right to privacy and the risks of health data commercialization and profiteering for the right to science. It reveals how commercial data-driven research in health generates a number of concerns that span civil and political and economic,

[352] UN OHCHR (n83); UNHRC 'The right to privacy in the digital age: Report of the United Nations High Commissioner for Human Rights' (3 August 2018) UN Doc A/HRC/39/29; 'How AI affects human rights' (n81).
[353] Latonero (n82); McGregor et al (n82).
[354] Dove & Özdemir (n84).
[355] Knoppers et al (n86); Harris & Wyndham (n86).

social and cultural rights. However, despite acknowledgement of the relevance of the right to health in this area, it has received little attention from human rights scholars to date. In the final section, I highlight this gap in the literature, which this thesis seeks to address.

2.3.2. Health data misuse: implications for the right to privacy

2.3.2.1. The right to privacy in the digital age and its application to health data

Health data has typically attracted special attention from privacy advocates due to its sensitive and personal characteristics.[356] Furthermore, the protection of patient privacy in healthcare has long been subject to legal and ethical rules like confidentiality and consent.[357] Despite this, the growing use of health data in medical and scientific research involving technology companies poses novel threats to the right to privacy, which have been a primary focus of the human rights community's response to developments in data-driven health innovation.

The right to privacy is enshrined in Article 12 of the UDHR and Article 17(1) of the UN ICCPR,[358] which states, "No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful

[356] Björg Thorarensen 'The processing of health information- protecting the individual right to privacy through effective legal remedies' (2017) Health Technol 7 401-413.
[357] UN OHCHR 'Explanatory Memorandum to the Recommendation on the Protection and Use of Health-Related Data' (4 October 2019) <www.ohchr.org/Documents/Issues/Privacy/SR_Privacy/MediTASFINALExplanatoryMemoradum1.pdf> accessed 7 August 2020.
[358] UDHR (n100); International Covenant on Civil and Political Rights (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171 (ICCPR).

attacks on his honour and reputation". The content of the right to privacy has been expanded through the work of the Committee on Civil and Political Rights (CCPR).[359] Furthermore, the right to privacy legal framework has been strengthened through inclusion in regional human rights instruments and domestic human rights legislation.[360]

Recent technological advances have proven vulnerable to surveillance and interception, generating renewed interest in the right to privacy 'in the digital age',[361] "a euphemistic term which emerged to encapsulate the relationship between privacy, surveillance and the protection of personal data—particularly in the context of digital technologies and the internet".[362] The right to privacy in the digital age has since been at the top of the agendas of both regional and international human rights mechanisms.[363] In 2015, the UN appointed a Special Rapporteur on the Right to Privacy in the Digital Age, Professor Joseph Cannataci, with a mandate to explore the promotion and protection of the right to privacy in the context of new information technologies.[364] Since his appointment, the Special Rapporteur has addressed a number of concerns relating to commercial data misuse and the right to privacy, including health data.

In his work on health data,[365] the Special Rapporteur acknowledges the growing importance of digital data in preventing and treating health conditions and

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[359] UNHRC 'CCPR General Comment No. 16: Article 17 (Right to Privacy), The Right to Respect of Privacy, Family, Home and Correspondence, and Protection of Honour and Reputation' (1988) UN Doc HRI/GEN/1/Rev.9.
[360] Regional human rights instruments that protect the right to privacy include the ECHR (n30) and the American Convention on Human Rights (adopted 22 November 1969, entered into force 18 July 1978) OAS Treaty Series No 36 1144 UNTS (ACHR). The right to privacy is also enshrined in domestic legislation in many countries.
[361] UN OHCHR (n72).
[362] Carly Nyst & Tomaso Falchetta 'The Right to Privacy in the Digital Age' (2017) J Hum Rights Pract 9(1) 104-118, 104.
[363] Ibid.
[364] UN OHCHR (n83).
[365] UN OHCHR (n357).

our “shared interest in our dignity and autonomy being protected by the highest standards in health-data related scenarios”.[366] He further acknowledges that health data has applications for other stakeholders beyond healthcare, resulting in tensions between different interests that give rise to social, legal and ethical issues.[367] In response to these challenges, the Special Rapporteur- alongside the purposely-established Task Force on Privacy and the Protection of Health-Related Data- published the Recommendation of the Protection and Use of Health-Related Data in December 2019,[368] intended to serve as “a common international baseline for minimum data protection standards for health-related data”.[369]

The Recommendation describes the legal conditions for processing health data and addresses health data use in specific contexts, including scientific research. The recommendation on scientific research highlights the need for appropriate safeguards, consent, anonymisation and the right to “prior, transparent and comprehensible” information,[370] and suggests researchers must weigh up a number of factors in evaluating health data processing; these include the purpose of the research, respect for ethical rules, its purported benefits and potential risks to the data subject or for group harm.[371]

The Special Rapporteur also addressed commercial misuse of health data in his end of mission statement on his visit to the UK in 2018. Here, he drew attention to the privacy risks of the DeepMind-Royal Free partnership, highlighting the decentralised nature of the NHS and inexperience of some trusts as a barrier to

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[366] Ibid 2.
[367] Ibid 3.
[368] UN OHCHR ‘Recommendation on the Protection and Use of Health Data’ (5 December 2019) <https://www.ohchr.org/Documents/Issues/Privacy/SR_Privacy/UNSRPhealthrelateddataRecCLEAN.pdf> accessed 7 August 2020.
[369] Ibid 3.
[370] Ibid 25.
[371] Ibid 25.

negotiating effective data-sharing partnerships and arguing for "clear, strong guidelines on and oversight of any data-sharing agreement entered by the NHS".[372] He thus concludes that, "while there are benefits to private-public partnerships, all data-sharing must be done with strict respect to the right to privacy of all patients and data-sharing standards including the Data Protection Act".[373]

2.3.2.2. Human rights scholarship on commercial health data misuse and the right to privacy

This institutional response to commercial data-driven health research reflects the concerns of right to privacy scholars, who warn of the erosion of privacy that has accompanied advancements in biomedical and technological research in health. Petersen argues that the Big Data revolution has rendered health data- even in its anonymised form- far less private;[374] thus, even where governments make concerted efforts to protect patient confidentiality, "we should assume those measures will be fallible".[375] Lobato de Faria and Cordeiro echo Petersen's sentiment, describing the right to health data privacy as "more of an academic figure than a real protected right".[376]

For right to privacy scholarship in this area, the issue of transparency is a primary concern. Vayena and Tasioulas suggest that the opacity of commercial actors' computational tools reinforce the importance of privacy protections against

[372] UN OHCHR 'End of Mission Statement of the Special Rapporteur...'' (n83).
[373] Ibid.
[374] Petersen (n95).
[375] Ibid 22.
[376] Paula Lobato de Faria & João Valente Cordeiro 'Health data privacy and confidentiality rights: Crisis or redemption?' (2014) Rev Port de Saude Publica 32(2) 123-133, 123.

corporate actors.[377] This lack of transparency is also condemned by Dove and Özdemir,[378] who argue that operating in a 'black box' will fail to establish public trust; any initiative wishing to do so, they contend, "must be willing and able to explain openly and clearly what data are being held, what proportionate privacy and security controls are imposed on them, with whom these data are being shared, and why, all reinforced and constantly updated with proper evidence".[379]

Dove and Özdemir also highlight the importance of accountability in protecting the right to privacy in commercial data-driven health research. The authors describe the close link between participation and accountability, arguing that, "any data initiative or data sharing system that is centered on holding the public's trust must be willing and able to listen to, deliberate on, and respond to the questions and comments posed by publics, and potentially incorporate their input on a meta-governance level".[380] These participation rights, they argue, "necessitate a priori transparency obligations".[381] The authors further argue that, for accountability to be effective, "one must be able to follow the lines of responsibility throughout the course of data flow (i.e., in whose hands it has been placed, and in whose hands it will be placed), and those actors involved in the flow must be able to explain and justify their conduct at all times in front of a forum that can pose questions and pass judgment, and impose consequences on those actors".[382]

Right to privacy scholars have also drawn attention to the close relationship between privacy and other human rights in the context of commercial misuse of health data, particularly the right to non-discrimination. Ursin explains how health

[377] Vayena & Tasioulas (n85).
[378] Dove & Özdemir (n86).
[379] Ibid 529.
[380] Ibid 529.
[381] Ibid 530.
[382] Ibid 530.

data can be misused by companies to "control, deceive, or harm",[383] leading to the violation of the right to non-discrimination in medical research. Petersen substantiates this link in the context of health data related to disabilities, documenting how the misuse of data collected through voluntary contribution or wearable devices can lead to discrimination against disabled people by commercial actors in the finance, retail or employment sectors.[384] She argues for a stronger enforcement model to dissuade commercial health data misuse and calls on governments to adopt a proactive approach in requiring private actors to disclose practices of re-identification and purchase of health data.[385]

The right to privacy in the context of commercial health data misuse is also closely related to economic, social and cultural rights like the rights to science and health. For some privacy scholars, this relationship is conceptualised as a tension between privacy protection and public health; for example, Di Iorio et al argue that the EU Data Protection Regulation- intended to strengthen the standing of the right to privacy- may restrict the ability of researchers to link data across sources, thus compromising the right to health.[386] Chan et al also acknowledge this tension between societal benefits and privacy protection, praising the UK National Data Guardian as an exemplary regulatory model in balancing these interests.[387]

Together, this body of scholarship and the work of Special Rapporteur on Privacy in the Digital Age highlight the novel risks that data-driven research in health pose to civil and political rights like the rights to privacy and the need for health data governance and regulatory systems to adapt accordingly. An exclusive focus on the

[383] Lars Øystein Ursin 'Biobank research and the right to privacy' (2008) Theor Med Bioeth 29(4) 267-285.
[384] Petersen (n97).
[385] Ibid.
[386] Di Iorio et al (n88).
[387] Chan et al (n88).

risks of health data misuse, however, neglects other important issues arising from the commercial use of health data in research, which implicate a broader range of economic, social and cultural rights. The following section thus shifts focus to the problematic consequences of health data commercialisation and profiteering for the right to science.

2.3.3. Health data commercialisation and profiteering and the right to science

2.3.3.1. The right to science

The right to science is contained in both Article 27 of the UDHR and Article 15(b) and (c) of the UN ICESCR[388], which states, "The States Parties to the present Covenant recognize the right of everyone... (b) To enjoy the benefits of scientific progress and its applications; (c) To benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author".[389] Article 15(b) is inclusive of new technologies protected by patents;[390] as such, UN committees and special mechanisms for the right to science have paid particular attention to issues around IP, which are integral to processes of health data commercialization and profiteering.

In its statement on human rights and IP, the CESCR acknowledged "the broad significance of the creation, ownership and control of intellectual property in a

[388] UDHR (n100) art 27; ICESCR (n101) art 15.
[389] ICESCR (n101) art 15 (b) & (c).
[390] UNGA 'Report of the Special Rapporteur in the field of cultural rights' (4 August 2015) UN Doc A/70/279.

knowledge-based economy and the means that it can afford for promoting or inhibiting the enjoyment of human rights".[391] The report encouraged the development of IP systems in a 'balanced manner' and emphasised that "intellectual property is ultimately a social product and has a social function":[392] to facilitate human well-being.

The former Special Rapporteur in the field of cultural rights has also addressed the relationship between IP and the right to science.[393] In a 2015 report, she highlighted tension between the two clauses of the right to science, arguing that the right to protection of the moral and material interests of authors should not override the right to enjoy the benefits of scientific progress and other related human rights like the right to health. Thus, she states, "the objective of intellectual property rights law is not to provide the maximum possible return to rights holders, but to strike the proper balance of private and public interests".[394] The Special Rapporteur further stressed the importance of transparency in relation to IP, encouraging companies to disclose financial information about their R&D activities. The human rights approach to patents, she claims, draws attention to important but otherwise overlooked issues such as the social function of IP, the public interest, participation in policymaking, the promotion of innovation and the impact of patent regimes on marginalised groups.

In this report, the Special Rapporteur also emphasised the risks patent policy poses to health equity, underscoring the imperative for states to ensure access to essential technologies for all- particularly the most marginalized- and arguing that a human rights perspective may judge patent exclusivity to be arbitrary, discriminatory

[391] UN CESCR (n87) 2.
[392] Ibid 2-3.
[393] UNGA (n390)
[394] Ibid 17.

or disproportionate on the basis of the extent of its rights violations or facilitation of corporate profiteering. Ensuring access to technologies through the appropriate funding structures and processes, she suggests, is particularly important where research has received subsidy from states, intergovernmental organizations or NGOs.[395]

In April 2020, the CESCR reaffirmed the close relationship between IP, access to health technologies and the right to science in General Comment 25.[396] The Committee drew attention to the growing involvement of commercial actors in scientific research, highlighting how IP can have negative impacts on the enjoyment of the right to science by redirecting research towards profitable projects as opposed to those addressing fundamental socio-economic rights and allowing patent holders to set high prices that compromise the financial accessibility of new scientific innovations.[397] The Committee encourages states to counteract the risks of IP systems by providing adequate financial support to research that advances socio-economic rights, balancing IP and open access and sharing of scientific benefits, and preventing unreasonably high costs of scientific products.[398]

2.3.3.2. Right to science scholarship on health data commercialization and profiteering

[395] Ibid.
[396] UN CESCR 'General comment No.25 (2020) on science and economic, social and cultural rights (article 15(1) (b), (2), (3) and (4) of the International Covenant on Economic, Social and Cultural Rights)' (n87).
[397] Ibid, para 61.
[398] Ibid, para 62.

Right to science scholars have drawn attention to the risks that IP systems pose to the right to science in data-driven health research. Vayena and Tasioulas highlight how IP rights may limit the dissemination of the fruits of data-driven research, which "risks according disproportionate weight to one part of the right, thereby making the other part of it impossible or unduly burdensome to exercise"[399]. The authors acknowledge competing IP interests in health data and their outcomes, arguing that these should not compromise other interests or rights that warrant protection.[400]

One such interest is equitable access to health technologies. Harris and Wyndham stress that the results of data-driven research in health should be used in a way that benefits everyone.[401] Similarly, Knoppers et al propose accessibility as a key criterion to govern data sharing in commercial data-driven research; by properly acknowledging the use of data resources, the authors argue, commercial data users are discouraged from using patents to block access to data or the benefits drawn from it.[402]

Right to science scholars have further highlighted the obligation for states to generate the maximum possible benefits from data-driven health research. In contrast to privacy scholars- who have tended to focus on the State's obligations to protect the right to privacy- right to science scholars have keenly emphasised the State's positive obligations with regards to the use of health data in research. Knoppers et al contend that data sharing is essential for ensuring scientific research maximises benefits to public health and society;[403] they regard it both as part of "the

[399] Vayena & Tasioulas (n85) 14.
[400] Ibid.
[401] Harris & Wyndham (n88).
[402] Bartha Maria Knoppers et al 'Towards a data sharing Code of Conduct for international genomic research' (2011) Genome Med 3(7) 46.
[403] Ibid.

efficient and proper stewardship of funds" and a means of ensuring "a just return on public investment and participation".[404] Donders similarly underscores the essential nature of scientific and technological research for advancing the right to health, arguing that States have a legal obligation to "invest, to the maximum possible, in scientific and technological advancement and share the benefits".[405]

Transparency and accountability are also critical concerns in this literature. In their human rights approach to data sharing, Harris and Wyndham call for transparency in "the processes and regulatory systems established to manage data collection, storage and dissemination"[406]. Knoppers et al's code of conduct focuses primarily on transparency in commercial dealings, demanding that policies on publications, IP, commercial involvement and information on progress and results are made available to the public through accessible websites.[407]

For some, fostering accountability is deemed a particular strength of the human rights approach to commercial data-driven health research. Knoppers et al suggest that "ethical norms alone lack the articulation of the force of governmental and other regulatory stakeholder duties and standards of accountability" associated with human rights,[408] encouraging the establishment of flexible oversight and monitoring systems and ongoing public engagement.[409] This is supported by Mann and Schmidt, who emphasise the importance of states engaging in participatory health research, which actively involves all stakeholders and ensures their voices are prominent in discussions around priority-setting.[410] However, commercial actors also

[404] Ibid 48.
[405] Donders (n87) 375.
[406] Harris & Wyndham (n88) 336.
[407] Knoppers et al (n402).
[408] Ibid 899.
[409] Ibid.
[410] Mann & Schmid (n87).

have right to science obligations in data-driven health research;[411] Knoppers et al stress that non-state actors like commercial organisations should also respect regulatory efforts based on the human rights framework in this context.[412]

Right to science institutional and scholarly responses to commercial data-driven health research highlight how health data commercialisation and profiteering implicate human rights beyond the bounds of civil and political rights. Furthermore, by framing data-driven health research "as a public good that enhances human capabilities and economic productivity"[413] and "an ethical and scientific imperative",[414] right to science scholars shift emphasis to the state's positive obligations with respect to health data. Their contributions also demonstrate the potential utility of the international human rights legal framework in balancing competing interests in health data and governance efforts in this area.

2.3.4. The right to health in commercial data-driven health research

The preceding sections reveal how the involvement of commercial actors in data-driven health research poses economic and political risks that implicate civil and political and economic, social and cultural rights. Across this literature, a number of scholars suggest the right to health may be particularly relevant in the context of commercial data-driven health research.[415] Furthermore, many of the key issues

[411] Donders (n87).
[412] Knoppers et al (n88).
[413] Ibid 899.
[414] Ibid 895.
[415] Ibid; Petersen (n95).

identified here implicate cross-cutting human rights principles that are also key components of the right to health, implying that commercial data-driven health research may also significantly impact the right to health.

The importance of the connection between the right to health and data-driven innovation is supported by the CESCR's publication of General Comment 25 in April 2020,[416] which explores the relationship between science and economic, social and cultural rights. Here, the Committee acknowledge the significance of new technologies like AI for socio-economic rights like the right to health, arguing that "States parties have to adopt policies and measures that expand the benefits of these new technologies while at the same time reducing their risks".[417] The Committee emphasise the need for the development and use of these technologies- and the regulation and governance of the data underlying their development- to be guided by the international human rights framework.[418]

Despite its clear relevance in this context, however, the implications of commercial data-driven health research for the right to health had scarcely been explored in the human rights literature until as late as December 2020, when the Health and Human Rights journal published a special issue on the relationship between AI, big data and the right to health.[419] Davis and Williams' introduction to the special issue acknowledges how exploration of the impact of technologies on social rights to date has been limited and summarises the subsequent articles, many

[416] UN CESCR 'General comment No.25 (2020) on science and economic, social and cultural rights (article 15(1) (b), (2), (3) and (4) of the International Covenant on Economic, Social and Cultural Rights)' (n87).
[417] Ibid, para 74.
[418] Ibid, para 74 & 76.
[419] HHR Journal Special Issue (n97).

of which touch upon issues related to commercial data-driven health research and the right to health.[420]

Sekala et al assess the human rights dimensions of digital public health surveillance of COVID-19.[421] The authors identify four primary human rights concerns arising from digital surveillance tools in the COVID crisis; their efficacy, the involvement of private actors, discrimination and the exacerbation of inequality, and the risks of context transgression. Of particular relevance here, they argue that the involvement of commercial actors in digital health technologies poses questions of accountability and that the commercialization of health data risks future discriminatory exclusions and differential pricing by insurance companies.

For digital health surveillance tools to comply with human rights, the authors contend, they must be "evidence based, contribute to a comprehensive public health surveillance system, include sunset clauses, be non-discriminatory, and ensure mechanisms for greater transparency and accountability, including those aimed at nonstate actors such as private companies".[422] Appropriate transparency and accountability mechanisms include "increased participation from a diversity of end users in the design and rollout of apps, independent oversight through civil society organizations, increased research into the human rights effects of these apps, and greater accountability for the holders of data, including third parties".[423] The authors further draw attention to the potential of national action plans as a means of strengthening the realization of human rights through public policy and technology companies' responsibility to conduct human rights due diligence. They conclude that

[420] Davis & Williams (n98).
[421] Sekalala et al (n98).
[422] ibid, 14.
[423] ibid, 15.

further empirical research into accountability in this context is necessary, particularly where data may be commercialized or deanonymized in the future and call for relevant UN Special Procedures and treaty bodies to give greater attention to the growing role of private corporate actors in digital health surveillance.

Sun et al's article focuses more generally on the relationship between human rights and digital health technologies.[424] Like Sekalala et al, these authors summarise the key harms relating to digital health technologies, including data breaches, bias and discrimination, and function creep; partnerships between governments and private technology companies, they suggest, have raised alarms relating to function creep where data may be exploited for surveillance or commercial purposes.

The authors state that the adoption of digital health technologies must be aligned with the right to health, including the AAAQ framework. They argue that emerging technologies raise particular concerns relating to the accessibility and availability of technologies, which may inadvertently exacerbate inequalities and widen digital divides. To address these risks, they propose that states and technology companies proactively identify risks of discriminatory outcomes, states hold companies accountable for identifying, mitigating and redressing these risks, and ensure transparency and accountability in the development, adoption, implementation and evaluation of digital health technologies.

Sun et al propose three opportunities to assess whether ethical principles and human rights protections have been given sufficient consideration in the adoption of digital health technologies; health technology assessments, national digital health strategies, and judicial review. They further emphasize the need for governments to

[424] Sun et al (n98).

directly address inequities in access and advance transparency through digital health interventions. Leveraging the potential of digital health technologies, they conclude, "requires the meaningful adoption of standards and principles that ensure that these technologies truly protect rights, empower individuals, and do no harm".[425]

Sara Davis' article adopts Philip Alston's concept of a 'trojan horse' to highlight how the rapid proliferation of digital health technologies in global health is accompanied by serious and often covert social effects that require greater consideration by states.[426] Among the risks she identifies, David argues that digitization in health may prove a trojan horse for the private sector, highlighting how technology companies can benefit significantly from public-private partnerships in which there is no immediate financial gain, raising questions about the appropriate use of taxpayer funds. She concludes that "it is critical that respect for human rights move to the center of digital health governance and not be left as an afterthought".[427]

By contrast to these articles, which focus predominantly on identifying the risks emerging from digital health technologies, Williams focuses on developing a guide for health rights impact assessments as a means of strengthening the realization of the right to health in artificial intelligence projects.[428] She highlights the now widespread use of AI in healthcare and argues that, regardless of the context, AI health projects must be proceeded by a systematic health rights impact assessment that moves beyond civil and political rights concerns to consider the effect it will have on right to health principles and the broader health system. Its purpose, the author suggests, is both to strengthen AI projects to ensure they are

[425] Ibid, 29.
[426] Davis (n98) 41.
[427] ibid 45.
[428] Williams (n98).

aligned with broader health system objectives and to strengthen health systems at large by ensuring AI projects are sustainable and advance the right to health.

Williams' proposed framework includes questions on a broad range of impacts, including legal context, health services, goods and facilities, health workforce, health information systems, medical products, vaccines and technologies, national financing and governance and leadership. She argues that her framework deliberately looks beyond the 'technocratic' aspects of the health system to consider the impact of AI projects on key right to health principles, including participation, accountability, equality and non-discrimination, non-retrogression, and international cooperation. In this respect, her work provides the most comprehensive and holistic tool to assess the right to health impacts of commercial data-driven research projects to date.[429]

As a whole, the right to health scholarship relating to commercial data-driven research reveals shared concerns about the risks that data-driven research poses to the right to health, particularly equitable access to healthcare and accountability. However, as most of the literature to date focuses largely on preliminary exploration or mapping of these risks, there is little empirical evidence or case study analysis of the impacts of commercial data-driven research on the right to health.

2.4. Conclusion

This section reviewed the human rights scholarship on commercial data-driven research in health. First, it explored the relationship between health data

[429] Ibid.

misuse in data-driven health research and the right to privacy, arguing that the privacy scholarship and the work of Special Rapporteur on Privacy in the Digital Age highlight novel risks that data-driven research in health pose to civil and political rights. It then turned to the commercialization of health data and its implications for the right to science, revealing an emerging body of socioeconomic rights scholarship that shifts emphasis to the state's positive obligations with respect to the use of health data. Finally, it reviewed the limited right to health literature relating to commercial data-driven research in health, arguing that it both reveals common underlying concerns around equity and accountability while also lacking empirical, case study analysis of its impact of the right to health in practice.

Chapter 3: Methods

3.1. Methodology

My research adopts a case study methodology, focusing in on one exemplary data-driven research partnership; the collaboration between DeepMind Health and the NHS. The case study is "an empirical inquiry that... investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident".[430]

I adopted the case study methodology to answer my research question as it enabled me to explore the multitude and complexity of facets that make up data-driven research partnerships, painting a rich picture of a contemporary phenomenon that is as-of-yet little theorised in academic scholarship. This was facilitated by my use of an interdisciplinary framework, through which I synthesized findings on the case study from a variety of theoretical perspectives. Further to this, my research explores questions of political economy and socioeconomic rights, which necessarily implicate political, economic and legal systems. Case study methodology enabled me to retain important contextual characteristics of the DeepMind-NHS collaboration- including its political, economic and legal context- thus lending itself to the analysis of the structural implications of data-driven research partnerships. Together, the rich, contextual picture generated by my use of case study produces the in-depth insights necessary to answer my research question, which is exploratory in nature.

[430] Robert Yin, 'Case Study Research: Design and Methods' (1994) Second Edition (Thousand Oaks, CA: Sage).

3.2. Research Methods

My methodological approach combined documentary analysis of grey literature and semi-structured interviews. In total, I analysed over 150 documents[431] and conducted 19 in-depth, semi-structured interviews with key stakeholders in the DeepMind-NHS partnership and opinion-leaders in the area of data-driven research partnerships. This combination of research methods enabled me to triangulate findings across different sources, thus reducing bias present within each data set.[432]

This methodological approach stems from my project's epistemological basis in the interpretivist paradigm. In contrast to the positivist epistemology underlying the natural sciences- which posits that there is a natural reality distinct from social interaction which can be observed in a detached, value-free way-[433] interpretivists propose that the understanding of causation is developed through an interpretative understanding of social action as opposed to the identification of consistencies and regularities.[434] As such, interpretivists are concerned with "culturally derived and historically situated interpretations of the social life-world".[435] Interpretivism is predicated on the ontological premise that reality is socially constructed, multiple and relative; thus, phenomena can only be understood through the contextual understanding and interpretation of different actors' perspectives or perceived knowledge.[436]

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[431] See Annex 1 for comprehensive list of sources
[432] Glenn A. Bowen, 'Document Analysis as a Qualitative Research Method' (2009) Qual Res J 9(2) 27-40.
[433] Michael Crotty 'The Foundations of Social Research: Meaning and Perspective in the Research Process' (1998) (London: Sage).
[434] Ibid.
[435] Ibid 67.
[436] David Carson et al, 'Qualitative Marketing Research' (2011) (London: Sage).

3.2.1. Document Analysis

Document analysis refers to "a systematic procedure for reviewing or evaluating documents- both printed and electronic (computer-based and Internet-transmitted) material".[437] This entails the examination and interpretation of documents in order to decipher meaning, gain understanding and produce empirical evidence. Document analysis is predicated on the idea that documents are 'social facts' or 'artefacts';[438] that is, they are created for a specific purpose and function, and are thus the embodiment of actions and interactions within social settings. In this sense, documents are socially produced and consumed and both "resources to be mined and topics to be studied".[439] This calls for researchers to go beyond determining the existence and accessibility of documents to analyse their authenticity and usefulness and consider their original purpose, context and intended audience.[440]

I chose to use document analysis as it enables the researcher to produce a rich description of a specific phenomenon or event, making it well-suited to case study research.[441] This was particularly true of the DeepMind-NHS case as- unusually for a commercial deal of this kind- much of the grey literature surrounding the case was publicly available due to the investigative work of journalists and other stakeholders. Document analysis in this context thus provided both an extensive and novel source of data on data-driven research partnerships. Document analysis also

[437] Bowen (n432).
[438] Amanda Coffey 'Analysing Documents' in Uwe Flick (ed) *The SAGE Handbook of Qualitative Data Analysis* (SAGE Publications Ltd, 2013) 367-379.
[439] Coffey (n438).
[440] Bowen (n432).
[441] Yin (n430).

offers the practical advantage of being more efficient than other research methods, a factor I deemed particularly important in light of the need to keep pace with real-time developments in the case study.[442]

3.2.2. Semi-Structured Interviews

Semi-structured interviews are a form of qualitative interview in which the researcher uses an interview guide but is free to adapt this to fit the flow of conversation;[443] thus, "far from being an impersonal data collector, the interviewer, and not an interview schedule or protocol, is the research tool".[444] In semi-structured interviews, the researcher must adopt a conversational tone and ask open-ended questions that are designed to elicit 'rich talk'; that is, inviting interviewees to speak at length about their experiences, memories, reflections and opinions, and develop their thoughts as they wish.[445]

I chose to use semi-structured interviews in support of my document analysis. The confidentiality of the interview setup provided an opportunity to elicit novel insights into the DeepMind-NHS case, as participants could disclose information unavailable in the public domain. Conducting semi-structured interviews thus helped to overcome the limitations of document analysis alone, which relies on publicly-accessible information. This was particularly important given the controversial and politically charged nature of the DeepMind-NHS case.

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[442] Ibid.
[443] Eva Magnusson & Jeanne Marecek, 'Doing Interview-based Qualitative Research' (2015) (Cambridge University Press).
[444] Steven J. Taylor et al, 'Introduction to Qualitative Research Methods: A Guidebook and Resource' (2015) (John Wiley & Sons Inc).
[445] Magnusson & Marecek (n443).

Further to this, the spontaneous and dialectic nature of semi-structured interviews can also encourage participants to engage critically and interactively with the research topic, with the potential to generate entirely novel insights.[446] Using semi-structured interviews thus enabled me to elicit critical perspectives on the DeepMind-NHS case that helped me to identify the key issues it raised. Interviews are also a useful tool to reconstruct past events;[447] they therefore also helped to corroborate factual information surrounding the timeline of the partnership.

3.3. My Methods

3.3.1. Document analysis

My document analysis focused on the grey literature surrounding the DeepMind-NHS collaboration; this includes contractual agreements, magazine and newspaper articles, website material from DeepMind and the NHS (including press releases, blogs, and reports) and articles, blogs and reports from non-governmental organisations and regulatory bodies.[448] I selected which literature I would include on the basis of its relevance to the DeepMind-NHS case, the level of information it provided and its public availability. I also tried to include a wide range of sources that represented the views of a diversity of stakeholders to provide the richest possible picture of the case study.

However, as the case study unfolded in real time, the availability of different sources varied throughout the project, posing a challenge to my analysis. In

[446] Mira Crouch & Heather McKenzie 'The logic of small samples in interview-based qualitative research' (2006) Soc Sci Inf 45(4).
[447] Taylor et al (n444).
[448] For a full list of grey literature, see Annex 1.

particular, contractual agreements between the NHS, DeepMind and Google- which were at one time published on DeepMind's website- were taken down, preventing me from accessing them further. Where such instances occurred, I mitigated their impact by sourcing these documents through alternative avenues, including online Freedom of Information requests made by other researchers.

Further to this, in November 2016 and January 2018, DeepMind Health ran public and patient engagement events, which would have provided a first-hand account of the company's participatory efforts and a rich source of documentary data. Despite this, the events were not open to the general public at large and I was therefore unable to attend. To make up for this, I was able to access videos of both these events on the company's Youtube channel, allowing me to refer to their content in my document analysis.[449]

3.3.2. Semi-Structured Interviews

I began recruiting interviewees by instigating contact with key stakeholders in and commentators on the DeepMind-NHS case, which I identified through preliminary online research. I chose to recruit key stakeholders as they provided an internal perspective on the case to shed light on its details, while commentators provided an external, more reflective viewpoint that helped me to draw out the key issues it raised. This initial interviewee selection instigated a process of snowball sampling, through which my early contacts facilitated further introductions to relevant

[449] DeepMind, 'DeepMind Health - Patient and Public Engagement Event' (20 September 2016) available at < https://www.youtube.com/watch?v=wBfBiD38x34 > (accessed 21 June 2021); DeepMind, 'DeepMind Health - What Patients Want From Tech: Patient Engagement Events 2017' (24 October 2017) available at < https://www.youtube.com/watch?v=WCjBXEjm4Cg ? (accessed 21 June 2021).

colleagues and acquaintances. This gave me access to a diverse range of interviewees spanning academia, policymaking, patient advocacy groups, non-governmental organisations (NGOs), journalists, the NHS and DeepMind's own Independent Review Panel (see table below).

My interviewee pool represents a wide range of perspectives on the DeepMind-NHS case. Despite this, I was unable to secure an official interview with representatives from DeepMind or the Royal Free NHS Foundation Trust. In my view, these stakeholders were less willing to participate due to their direct implication in the controversial aspects of the case. This highlights how critical voices were disproportionately more willing to participate in my research than those directly implicated in controversial aspects of the case, a fact I have tried to mitigate through the inclusion of grey literature representing the views of DeepMind and the Royal Free.

Further to this, I chose not to interview NHS patients directly in my research, as I felt they were not best placed to shed light on the details of the case- which requires insider knowledge- nor to comment on the key political economic issues it raises, which relies on relevant expertise in this area. Instead, I tried to incorporate the patient perspective by interviewing representatives of two patient advocacy groups, who possessed the knowledge and expertise necessary to voice the concerns of patients in relation to the specifics of the DeepMind-NHS case.

The following table lists the names of interview participants (using pseudonyms for those who wished to remain anonymous), the interest group they represent, their occupations (at the time of the interview) and dates of their interviews:

Name	Occupation	Date of Interview
Dr Subhajit Basu	Associated Professor in Information and Technology Law	12th January 2018
P2	Academic	23rd January 2018
Sam Smith	Policy Lead at MedConfidential	22nd February 2018
Dr Tamar Sharon	Assistant Professor at Radboud University	23rd February 2018
Theresa Harris	Project Director in the Scientific Responsibility, Human Rights and Law Program in the AAAS	26th February 2018
Hal Hodson	Journalist at *The New Scientist*	22nd March 2018
Dr Natalie Banner	Lead for Understanding Patient Data	20th March 2018
P8	Researcher at independent research institute	13th April 2018
Professor Julian Huppert	Head of DeepMind's Independent Review Panel	19th April 2018
Eleonora Harwich	Head of Digital and Tech Innovation at Reform	29th May 2018
Javier Ruiz	Policy Director at Open Rights Group	30th May 2018

P12	NHS clinician	15th August 2018
P13	Patient advocacy group	30th September 2018
P14	Academic	1st October 2018
Vivek Kotetcha	Research Manager at the Centre for Health and the Public Interest (CHPI)	8th October 2018
P16	Academic	17th October 2018
P17	Think tank	30th October 2018
Annemarie Naylor MBE	Director of Policy and Strategy at Future Care Capital	11th January 2019
Harry Evans	Policy Researcher at the King's Fund	15th January 2019

I conducted 19 interviews in total, each lasting an average of approximately 60 minutes and varying in length depending on the participant's availability. The interviews were all conducted in person or over video conference call except one, which took place over the telephone as this was the interviewee's preferred communication method.

For each interview, I prepared a set of guiding questions. Some questions were intended to elicit information about the details of the case study; for example, "could you describe to me what happened in the DeepMind-Royal Free deal?". Others were intended to shed light on some of the key issues it raised. I developed a list of key issues based on my early research into the partnership, particularly drawing on Powles and Hodson's article. These issues included data protection,

consent, intellectual property, equity, participation, transparency, and accountability. I tailored my guiding questions for each interviewee depending on their specific knowledge and expertise. I recorded all interviews on an audio recorder and later transcribed them myself.

3.3.3. Coding my data

Once I had transcribed my interviews and collected my grey literature, I downloaded the interview transcripts and documents into the computer programme NVivo, which I used to help me organise and code my data. The coding process began by developing a loosely-defined coding schema of 'nodes' based on key right to health themes of interest, as identified in my theoretical framework. As relevant passages of the text were coded under these headings, further sub-themes emerged, which were then incorporated into this coding schema. The coding schema was therefore adapted and refined on a continuous basis, developing in its richness and complexity.

This is exemplified by the keywords that made up this coding schema. The initial version of the coding schema included the following keywords; Equity, Resource Availability, Transparency, Accountability, Corporate Responsibility. In the final version of the coding schema, each of these broad categories contained at least two levels of subcategories; for example, under 'Equity' were the keywords 'pricing', 'fragmentation' and 'digital maturity', and under 'pricing' was 'redactions' and 'public statements'. The evolution of my coding schema throughout the coding process reflects the development and refinement of my thoughts and arguments, and helped to inform the final structure of my analysis chapters.

3.4. Limitations

My methodology and research methods are subject to certain limitations. Critically, the case study methodology does not usually produce scientifically generalizable results;[450] as such, rather than suggest my findings apply to all data-driven research partnerships, I instead argue that the DeepMind-NHS case highlights the potential implications of such partnerships for the right to health.

Furthermore, document analysis can be limited by the fact that documents may provide insufficient detail as they are not created for research purposes.[451] In my research, I found that certain forms of document- notably contractual agreements- were more challenging to interpret due to the use of technical language. Furthermore, some documents were hard to retrieve or had parts redacted. Bowen suggests that "the absence, sparseness, or incompleteness of documents should suggest something about the object of the investigation or the people involved";[452] in this vein, I have interpreted the inaccessibility of certain information as a research finding. Biased selectivity is a further limitation of document analysis; for example, "in an organisational context, the available (selected) documents are likely to be aligned with corporate policies and procedures and with the agenda of the organisation's principals".[453] I have tried to mitigate the risks of biased selectivity by referring to wide range of documents produced by

[450] Yin (n430).
[451] Bowen (n432).
[452] Ibid.
[453] Ibid.

authors and organisations with divergent aims and interests in the DeepMind-NHS case.

Semi-structured interviews are also limited by interviewer bias and the variability of rapport between interviewer and interviewee,[454] which I discuss more fully in the subsequent section on reflexivity. However, the use of document analysis- which is unobtrusive and non-reactive- helps counter such concerns.[455] Furthermore, there is a risk that interviewees generate 'unreal' responses, such that they are able to fabricate, exaggerate or distort information in their responses.[456] My use of document analysis in conjunction with semi-structured interviews helps to overcome this issue, enabling me to triangulate my research findings and corroborate evidence across different sources.

3.5. Reflexivity

The central role of the researcher in interpretative research calls for reflexivity or the researcher's recognition of the "partial, provisional and perspectival nature of knowledge claims".[457] Though there is no absolute consensus on how one might practice reflexivity, Mauthner and Doucet provide useful guidance on the topic; the authors suggest interpretivist researchers consider how the data collection and analysis processes are influenced by their own social location and emotional

[454] Crouch & McKenzie (n446).
[455] Bowen (n432)..
[456] Taylor et al (n444).
[457] Natasha S. Mauthner and Andrea Doucet 'Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis' (2003) Sociology 37(3) 413-431, 40.

responses to participants, their academic and personal history, and the interpersonal, political and institutional contexts in which they are embedded.[458]

With regards to my own social location, my age and status as a doctoral student had the strongest influence on my document analysis and interactions with interview participants. Throughout the process of conducting interviews in particular, I was conscious of being younger and less experienced than many of the stakeholders and opinion leaders I interviewed. This may have caused me to be less authoritative or commanding in my interviewing style, thus impacting the types of answers participants generated. However, interviewees predominantly gave insightful and enthusiastic responses to interview questions. Furthermore, my age and relative inexperience enabled me to be genuinely inquisitive and open-minded to interviewees' ideas.

Additionally, my own academic history in anthropology and human rights and my personal history of employment in health and human rights NGOs has impacted my collection and analysis of documentary and interview data. In particular, my experience researching corporate human rights abuses has inevitably caused me to treat the claims of corporate actors with caution. However, I have tried to critically evaluate all documents equally, questioning their reliability and credibility where there is evidence that it is appropriate to do so. My association with the University of Essex's Human Rights Centre and the Human Rights, Big Data and Technology project will also have influenced the willingness of interviewees to participate in my research and possibly affected the types of answers they provided; this likely contributed to the lack of engagement from actors directly implicated in the

[458] Ibid.

partnership, who may be more averse to engaging with scholars adopting a critical human rights perspective.

Finally, my data have been shaped not only by my own perspective but by the interaction between the interpersonal, political and institutional biases of research participants and the politically-charged DeepMind-NHS case. This influence was particularly strong given the proximity of some participants to the case study and its unfolding in real time. This inevitably affected the responses of interviewees and their willingness or ability to comment on or criticise particular aspects of the case.

3.6. Ethical Considerations

As my research involved collecting primary interview data, I was required to apply for ethical approval from the University of Essex's Ethics Committee. I submitted copies of my participant information sheet, which provides participants with details of the interview procedure, and my consent form, which I developed from the University's suggested framework. I also submitted an ethical approval form, which detailed my research outline and plans and addressed important ethical considerations.

Informed consent is a critical requirement in primary qualitative research methods like interviews.[459] This involves providing participants with information about the purpose of the research, who it is funded by, who the researchers are, how interview data will be used, and what is required of them.[460] Researchers should gain

[459] Jane Ritchie & Jane Lewis, 'Qualitative Research Practice: A Guide for Social Science Students and Researchers' (2003) (London: Sage).
[460] Ibid.

consent from participants multiple times throughout the research project;[461] for example, consent is required prior to undertaking interviews, but should also be sought if participants have opted to look over the use of their interview data prior to publication, or if interview data is reused for another purpose beyond the initial research aims. Anonymity and confidentiality were also key ethical concerns associated with my semi-structured interviews; where participants opted to remain anonymous, the researcher must avoid identifying them either directly or indirectly and code audio recordings and transcripts to protect participant identities.[462]

I provided each interviewee with a consent form and participant information sheet prior to their interview. The information sheet told them about the project, funders, researchers, interview protocol, and the procedures around data collection, storage and use. The consent form required participants to give written consent to the conditions of the project and also gave them the various options regarding anonymity, including: 1. I would like my real name to be used, 2. I am happy for my real name to be used but would like to check over the use of any quotes before publication, 3. I would not like my real name to be used, 4. I would not like any identifying details to be used in the above. All those who opted to be named or to check over quotes used prior to submission were contacted to ensure they were still happy to be named and those who wished to check over quotes were given the opportunity to do so and to amend them as they saw fit. I coded all recordings and transcripts to avoid breaches of confidentiality and ensured they were stored on the university's cloud system.

[461] Barbara DiCicco-Bloom & Benjamin F Crabtree 'The qualitative research interview' (2006) Med Educ 40(4) 314-321.
[462] Ritchie & Lewis (n459).

As interviewees were participating in a professional capacity, the predominant risks of unintentional harms were to the employment and reputation of participants. I described these risks in the participant information sheet. Furthermore, I tried to avoid asking personal questions beyond confirming participants' occupations and how they came to know about the DeepMind-NHS case study. Where information was disclosed that might have put participants' jobs or reputations at risk, I have been careful to exclude it from the thesis.

I also took measures to avoid unintentional risks to myself when conducting interviews. In my face-to-face encounters with participants, I arranged to meet them either in a public place or in the participant's workplace. This created an atmosphere of mutual professionalism and respect. Given the politically sensitive nature of the topic and the direct involvement of some interviewees in the case study, I was conscious of provoking emotional responses from participants. However, I only encountered a strong and unexpected emotional reaction in one interview, shortly after which I chose to bring the interview to a close to avoid causing the participant distress. I have since discussed the incident with the interviewee to establish what interview material they are happy to be included in the thesis.

Finally, access and permission were key considerations in relation to my document analysis. Fortunately, as a result of the efforts of individuals and organisations that preceded me in investigating the DeepMind-NHS case, much of the grey literature surrounding the partnership was in the public domain. This included documents that were at one time confidential, such as contractual agreements that had been subject to freedom of information requests. As a result, I was able to draw upon a wide range of publicly available grey literature without the need to gain permission.

Chapter 4: The DeepMind-NHS case: implications for political economy

This chapter explores the DeepMind-NHS case in depth and its political-economic implications. It includes sections on the promise of DeepMind-NHS, resource asymmetries, knowledge asymmetries and a conclusion. The terms ‘resource asymmetries‘ and ‘knowledge asymmetries’ describe two different forms of power asymmetry- a concept common to critical data studies and political economy- arising from the DeepMind-NHS partnership. I chose to categorize my findings under these terms as they allow me to distinguish between asymmetries in the distribution of resources and material wealth on the one hand and the distribution of information and knowledge on the other. This distinction facilitates subsequent discussion of the implications of DeepMind-NHS for the right to health in terms of its provisions concerned with resources distribution- including equity and resource availability- and those that are implicated in the asymmetric distribution of knowledge- including transparency, accountability and corporate responsibility.

4.1. The promise of DeepMind-NHS

4.1.1. Public benefits

Throughout DeepMind’s collaboration with the NHS, both parties have touted the potential mutual benefits of the partnership. In the MOU between DeepMind and the Royal Free NHS Foundation Trust, both sides committed to “establishing a broad ranging, mutually-beneficial partnership, engaging in high levels of collaborative

activity and maximising the potential to work on genuinely innovative and transformational projects".[463] Thus, as is typical of PPP models, the notion of mutual benefit is a key underlying rationale in the DeepMind-NHS collaboration.[464]

This implies that the partnership will deliver public benefits. In Clause 6.4.3. of the MOU between DeepMind and the Royal Free, the trust describes its hope to benefit from "a place at the vanguard of developments in what is widely viewed as one of the most promising technologies in healthcare, with the potential for great cost savings...".[465] This idea was supported by comments from one interviewee, who stated, *"An app like Streams can help and will free up doctors' time- there is no doubt about it".*

This sentiment was echoed by other NHS trusts who partnered with DeepMind Health. In Moorfields Eye Hospital NHS Foundation Trust's online announcement of its collaboration with the company, a Moorfields clinician suggested DeepMind Health's AI will provide faster diagnosis and more timely treatment.[466] Similarly, on the NHS University College London Hospital Foundation Trust's website, the trust describes its hope that their collaboration with DeepMind will ensure that the segmentation of CT and MRI scans "can be done more rapidly", which could "free up clinicians to spend even more time on patient care, education and research".[467] Together, these statements suggest that collaboration with DeepMind Health is expected to deliver public benefits in the form of improvements

[463] Royal Free London NHS Foundation Trust (n8) Clause 6.1.
[464] Hodge & Greve (n39).
[465] Royal Free London NHS Foundation Trust (n8) Clause 6.4.3.
[466] 'Excited To Announce A New Medical Research Partnership With Deepmind Health' (18th September 2019) <www.moorfields.nhs.uk/content/excited-announce-new-medical-research-partnership-deepmind-health> accessed 10 August 2020.
[467] 'Google Health UK Q and A' <www.uclh.nhs.uk/OurServices/ServiceA-Z/Cancer/RADIO/Pages/GoogleHealthQandA.aspx> accessed 10 August 2020.

in the efficiency of health services in the NHS. This reflects the importance placed on neoliberal values like cost-cutting and time-saving in the NHS.[468]

In addition to efficiency gains, improvements in the quality of NHS care is also an anticipated public benefit of the partnership. DeepMind's website states their commitment to "support and strengthen the delivery of exemplary care in the NHS" and ensuring that "its talented clinicians get the tools and support they need to continue providing world-class care".[469] DeepMind's NHS partners also tout potential improvements in quality of NHS care; for example, Moorfields suggest DeepMind's algorithm will lead to more accurate diagnosis of preventable eye conditions.[470] These statements imply that improvements in the health and wellbeing of patients are a key objective of DeepMind-NHS, appealing to the so-called 'vitalist' narrative underlying data-driven health innovation.[471]

The disruptive potential of new data-driven technologies and the reputational gains of working with a well-known technology company like DeepMind are also viewed by some as a key public benefit arising from the collaboration. Clause 6.4.2. in the MOU between DeepMind and the Royal Free NHS Foundation Trust outlines the trust's hope to benefit from "reputational gain from a strategic alliance with an unrivalled partner of the highest profile and expertise, focused on a highly impactful mission"[472]. Furthermore, the Health Secretary Matt Hancock has publicly praised DeepMind's work with Moorfields, praising the 'transformative' potential of DeepMind's work and their advancement of innovation through good data

[468] Sharon 'When digital health meets digital capitalism...' (n41); Mazzucato (n65).
[469] 'We are very excited to announce the launch of DeepMind Health' (n10).
[470] 'Excited To Announce A New Medical Research Partnership With Deepmind Health' (n466).
[471] Sharon 'When digital health meets digital capitalism...' (n41).
[472] Royal Free London NHS Foundation Trust (n8) Clause 6.4.1.

management.[473] These gains in innovation appeal to the so-called 'project' repertoire in data-driven innovation, which is often used to justify collaboration with large tech companies like Google.[474]

Despite this wealth of perspectives on the anticipated public benefits of the partnership, the MOU between DeepMind and the Royal Free reveals one notable omission; Clause 6.4.1.- the first, two-part clause describing what the trust hopes to gain from the partnership- has been redacted in the publicly-available version of the agreement.[475] Thus, despite the public accessibility of the MOU, some of the anticipated public benefits of the partnership- which may be of a commercially-sensitive nature- remain undisclosed to the general public, raising questions around the transparency of the deal.

Taken together, these findings reveal that DeepMind-NHS is expected to deliver public benefits in the form of improvements in the efficiency and quality of NHS services, the development of disruptive innovations and reputational gains for NHS partners. This illustrates how PPPs are framed as publicly beneficial and demonstrates how research collaborations involving large technology companies like Google are characterised by a 'panopoly of moral orientations', meaning these public benefits are framed in a diversity of ways.[476] The potential public benefits of partnerships like DeepMind-NHS may thus offer a means to advance the right to health.

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[473] Hannah Crouch 'Deepmind AI System 'Able To Identify Eye Diseases And Make Referrals' (*Digital Health*, 14 August 2018) <www.digitalhealth.net/2018/08/deepmind-ai-system-eye-diseases-moorfields/> accessed 10 August 2020; Stephen Armstrong 'Matt Hancock's Plan For An NHS Tech Revolution Is Doomed To Fail' (*Wired*, 8 September 2018) <www.wired.co.uk/article/nhs-matt-hancock-technology-innovation> accessed 10 August 2020.
[474] Sharon 'When digital health meets digital capitalism...' (n41).
[475] Royal Free London NHS Foundation Trust (n8) Clause 6.4.1.
[476] Hodge & Greve (n39); Sharon 'When digital health meets digital capitalism...' (n41).

4.1.2. DeepMind Health's engagement with CSR and ethics

DeepMind's website projects an image of a socially-responsible research organisation acting primarily in the public interest. This is reflected in their mission statement- to "make the world a better place"-[477] and commitment to "research and build safe AI systems that learn how to solve problems and advance scientific discovery for all".[478]

This image is supported by DeepMind's lack of profitability to date; the company's losses tripled to almost £94 million in 2017.[479] One interviewee explained how the company had compromised its short-term profitability in pursuit of its mission:

"We need to remember, of course, that DeepMind's aim is really blue sky; it's really esoteric. It is developing artificial general intelligence and they say that without any irony... That is a very blue-sky endeavour. DeepMind Health is really the most pragmatic and practical part of their organisation which is really trying to do applied stuff; AI for some sort of practical good. The real driving factor is this 'blue-sky' project of developing artificial general intelligence and to do that, you're going to have to want or be comfortable with having to lose some money because there's no immediate commercial payback on that type of endeavour."

[477] Stephen Armstrong 'The Computer Will Assess You Now' (2016) BMJ 355 i5680.
[478] 'Homepage' <https://deepmind.com> accessed 11 August 2020.
[479] Shona Ghosh 'Google's Deepmind Cutting Edge AI Unit Is Costing Millions' (*Business Insider*, 4 October 2018) <https://markets.businessinsider.com/news/stocks/google-deepmind-ai-unit-costs-millions-2018-10-1027590761> accessed 10 August 2020.

This initial lack of focus on commercialisation led the company's own Independent Review Panel- to which I turn my attention subsequently in this section- to suggest in their annual report that DeepMind may be better conceived of as a 'research lab', 'not for profit' or 'charitably-minded venture' as opposed to a commercial entity.[480]

The comments of one interviewee, who wished to remain anonymous, supported this view, likening the company to a social enterprise:

"If they want to act like social enterprises, that's fantastic. Wouldn't it be great if all companies wanted to act like social enterprises and combine the profit incentives and the efficiencies that you get from that with that kind of sense of purpose?"

The image of DeepMind as a socially-responsible, non-commercial organisation has been further fuelled by public perception of the company's co-founders, Demis Hassabis and Mustafa Suleyman. One interviewee spoke warmly of the company's bosses:

"They are lucky that they can do research and they have the financial might of Google to back them up. Also- and I think this is a credit to Mustafa and Demis- they were always very academically and AI-for-good minded. They both have very interesting backgrounds which are quite different from other founders. I think it's a testament to their strength of character and the type of personality they have in the organisation that the company took on that approach."

[480] Ben Dickson 'Deepmind's Losses Display The Challenges Of The AI Industry' (*TechTalks*, 12 August 2019) <https://bdtechtalks.com/2019/08/12/deepmind-losses-costs-of-ai/> accessed 11 August 2020; DeepMind Health Independent Review Panel Annual Report (n6)12.

Other interview participants also drew attention to this positive perception of DeepMind's leadership; Tamar Sharon described how Suleyman is seen as a 'civic activist' due to his experience working in the NGO and human rights sectors. These comments illustrate how DeepMind's co-founders are viewed not only as tech entrepreneurs but also philanthropists, pointing to the increasingly blurred distinction between private profit-making and public benefit in the data economy.[481]

DeepMind is also engaged in a number of corporate social responsibility initiatives intended to promote the ethical development and use of AI among companies working in the sector. Notably, the company was a founding member of the Partnership on AI, a technology industry consortium with the mission to "benefit people and society" through developing best practices, advancing public understanding of AI, and serving as an 'open platform' for engagement and discussion around AI-related issues.[482] The company have also partnered with NGO Article 36 to "explore the risks of intelligent systems in international human rights law and international humanitarian law".[483] This focus on corporate responsibility further contributes to the company's public image as a socially-responsible research organisation.

Beyond this general perception of DeepMind's public image, DeepMind Health took a number of notable steps to demonstrate their commitment to socially-responsibly behaviour, particularly since the public controversy surrounding the data transfer under the Royal Free Hospital NHS Foundation Trust. When DeepMind Health was established in 2016, it appointed an Independent Review Panel (IRP)

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[481] Sharon 'When digital health meets digital capitalism...' (n41); Prainsack (n69).
[482] 'Homepage' <www.partnershiponai.org> accessed 11 August 2020.
[483] 'Ethics & Society' <https://deepmind.com/applied/deepmind-ethics-society/partners/> accessed 11 August 2020.

with the goal "to maintain a publicly accountable profile that ensures we act with the greater public interest in mind".[484] The IRP was tasked with producing an annual report detailing areas in which DeepMind could be commended or should seek to improve, which was published in June 2017.[485] In this report, the IRP described itself as "entirely independent" and "self-governing", subject to no binding secrecy rules or non-disclosure agreements.[486]

During my interview with Professor Julian Huppert- who lead the IRP at the time of the interview- he explained how it operated:

"Nine of us were appointed. We're currently eight in strength and recruiting. We have access to whatever they're doing. We go in, talk to them, see things. We're not under any confidentiality requirements- that's quite important- and we have a budget to investigate them, which is almost unheard of."

His remark speaks to the novelty of this kind of voluntary accountability mechanism in the context of a commercial organisation. Another interviewee's comments reaffirmed this view:

"It's a credit to them that they set up the Independent Review Panel. I think it's probably a unique model. I think it was given £100,000 by DeepMind to spend as it wanted. It had absolute right to go in at any point unannounced and then inspect any aspect of DeepMind's operations; the only minor caveat being seeing individual

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[484] 'DeepMind Health Independent Reviewer's Pledge' <www.scribd.com/document/349230622/DeepMind-Health-Independent-Reviewers-Pledge-V2-Google-Docs-pdf> accessed 11 August 2020.
[485] Ibid.
[486] DeepMind Health Independent Review Panel (n6)

patient data, obviously. It gave DeepMind's board two days' notice of its report before it was about to publish it to make sure there wasn't any time for DeepMind to surreptitiously change their practices before the report came out. It was very much an investigatory type of panel and I think they went about it in the right way."

In addition to the IRP, DeepMind also made notable efforts to promote patient and public participation in their work. In the wake of the Royal Free controversy, the company organised a number of participatory activities, including an event with over 130 patients, carers and members of the public on 20th September 2016 and a Collaborative Listening Summit with 50 patients, NHS stakeholders and members of the public on 31st January 2018.[487] The stated purpose of these events was to involve patients and the public in determining how the company should conduct participatory work and to develop a set of principles to guide technology companies working in the NHS. Through this work, DeepMind Health co-designed a strategy for involving patients and the public in their work.[488]

Together, these findings highlight how DeepMind Health has generated a public image of a benevolent, socially-responsible research organisation. DeepMind Health's public image exemplifies the rise of what Prainsack terms 'health data entrepreneurism', where "many organizations in the health domain, and particularly

[487] DeepMind, 'DeepMind Health - Patient and Public Engagement Event' (20 September 2016) available at < https://www.youtube.com/watch?v=wBfBiD38x34 > (accessed 21 June 2021); DeepMind, 'DeepMind Health - What Patients Want From Tech: Patient Engagement Events 2017' (24 October 2017) available at < https://www.youtube.com/watch?v=WCjBXEjm4Cg ? (accessed 21 June 2021).

[488] Mustafa Suleyman & Rosamund Snow 'Co-designing a patient and public involvement and engagement (PPIE) strategy for DeepMind Health' (2016) <https://kstatic.googleusercontent.com/files/9e1c583880533f1c15d2f69613794f9510ed73fa400e1b49bab251d9e4867d7d7a000ff6e8b46cb13045a81f65b61e43e92ede14c131f482c0de75b87e20683c> accessed 11 August 2020; 'Collaborating with patients for better outcomes' (*DeepMind blog*, 19 December 2017) <https://deepmind.com/blog/article/collaborating-with-patients> accessed 11 August 2020.

those whose activities revolve around health information and digital health, do not fit into traditional binary categories such as public versus private, ethical versus unethical, or bottom-up versus top-down"[489]. It further highlights how "'doing good' is becoming an inalienable- not an additional- dimension of corporate activity".[490] In addition to this, DeepMind Health's establishment of an independent accountability mechanism to oversee its work with the NHS and engagement with public and patient participation implies that public-private partnerships between technology companies and public health systems may advance good governance values like transparency and accountability, as posited by some political economists.[491]

4.2. Resource asymmetries

4.2.1. Private sector benefits: Google Health's exclusive intellectual property rights

Despite claims that DeepMind-NHS will deliver mutual benefits, including public benefits to the NHS, the details of the contractual agreements underlying the collaboration give reason to question this. Clause 16.2. of the services agreement between DeepMind and the Royal Free Hospital NHS Foundation Trust states that:

"DeepMind shall own all the IPR subsisting in or covering (i) the FHIR API; (ii) the DeepMind Software; (iii) the Documentation; (iv) the Developments; and any

[489] Prainsack (n73) 115.
[490] Sharon 'When digital health meets digital capitalism...' (n41) 4.
[491] Brinkerhoff & Brinkerhoff (n39); Hood et al (n55); Reich (n59).

improvements, modifications, developments to and/or derivative works of any of the foregoing and including, for the avoidance of doubt, any other IPR which may be developed or created by or on behalf of DeepMind in the design, development and/or deployment of the FHIR API or the DeepMind Software or otherwise in the provision of the Services."[492]

Under its collaboration with the Royal Free, DeepMind thus has the right to retain all developed intellectual property relating to the Streams application. This corroborates Powles and Hodson's concern that DeepMind will keep all IP developed through its collaboration with the NHS, meaning "the knowledge DeepMind extracts from these public resources will belong exclusively to DeepMind".[493]

Further to this, more recent contracts between Google Health UK and the NHS- which arose out of DeepMind Health's merger with Google Health- similarly allocate all developed IP relating to the Streams application to the commercial organisation; Clause 16.2. of Google Health's restated services agreements with the Royal Free and Taunton and Somerset NHS Foundation Trust echoes the wording of the original services agreement between DeepMind and the Royal Free.[494]

Additionally, the company's AI research collaborations with the NHS are also set to provide exclusive intellectual property rights to Google Health UK. Clause 7.3.

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[492] 'Services Agreement between DeepMind Technologies Limited and Royal Free London NHS Foundation Trust' (2016) (contract no longer available online- pdf available from author)
[493] Powles & Hodson (n2) 362.
[494] 'Execution Version- Novation and Amendment Agreement' (2019) available at < https://www.whatdotheyknow.com/request/607620/response/1459239/attach/4/DeepMind%20novation%20with%20RFL%20Redacted%2023%20October%202019.pdf?cookie_passthrough=1 > (accessed 21 June 2020); 'Execution Version- Novation and Amendment Agreement' (2019) available at < https://www.whatdotheyknow.com/request/607622/response/1449343/attach/5/TSFT%20Redacted%20GHUK.PDF.pdf?cookie_passthrough=1 > (accessed 21 June 2020).

of the amended research collaboration agreement with Moorfields Eye Hospital NHS Trust entitles Google Health UK to "IP residing in the results and any technology, designs, works, inventions, software, data, techniques, algorithms, know-how or other materials developed as part of the research".[495] Further to this, Clause 7.4. gives the company "the exclusive right to Commercialise the Developed IP".[496]

In my interview with journalist Hal Hodson, he explained the implications of the company's rights to IP and its commercialisation:

"The thing is that all the intellectual property from that deal belongs to Alphabet. That's fine- that's how it should work, of course, because DeepMind belongs to Alphabet- but what it means is that if... Alphabet launches a product through Verily or something, Moorfields gets nothing."

His comment highlights how granting technology companies exclusive IP rights prevents the NHS from sharing in any future commercial benefits resulting from the collaboration. However, it also highlights a further concern; that any IP rights assigned to DeepMind or Google ultimately belong to their parent holding company, Alphabet Inc. As a result, partnerships like DeepMind-NHS risk facilitating the accumulation of intellectual property- and scientific knowledge- in the hands of just a few powerful technology companies.

Together, these findings reveal that the DeepMind-NHS partnership has granted exclusive rights to developed IP- and with it entitlements to any scientific and

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[495] GHUK/Moorfields Eye Hospital, 'Consolidated and Restated Research Collaboration Agreement' (2016) available at < https://www.whatdotheyknow.com/request/607623/response/1451781/attach/3/Moorfields%20Eye%20Hospital%20NHS%20Foundation%20Trust%20Google%20contract%20Restated.pdf?cookie_passthrough=1 > (accessed 21 June 2021).
[496] Ibid.

commercial benefits of the collaboration- to Google Health. They exemplify how technology companies like Google pursue an innovation strategy of 'data rentiership' "designed to capture and extract value through ownership and control of data as an asset".[497] These findings further support the view that corporations are able extract wealth through a system of socialized risk and privatized reward in public-private innovation, whereby they reap disproportionate rewards from collective innovation processes.[498] They highlight that technology companies' data-driven business models not only pose risks to the privacy of patients but also their ability to access the scientific and commercial benefits of their data's use. Affording Google Health exclusive IP rights to collaboratively-generated innovations thus calls into question the UK government's resource availability obligations under the ICESCR.

4.2.2. Public sector benefits: future costs to the NHS and inequitable access to technologies

In the publicly-available copy of the original services agreement between DeepMind Health and the Royal Free Hospital NHS Foundation Trust, Clauses 10.1 to 10.4 under the heading 'Charging and Invoicing' are redacted.[499] Similarly, in the transfer of the services agreement with Taunton and Somerset NHS Foundation Trust to Google Health, Clause 6- which details the costs of the collaboration- has been omitted in the version available online.[500] Furthermore, in Schedule 1 of the

[497] Birch et al (n40) 3.
[498] Mazzucato (n39); McGoey (n51).
[499] Services Agreement between DeepMind Technologies Limited and Royal Free London NHS Foundation Trust' (2016) (contract no longer available online- pdf available from author), Clauses 10.1 to 10.4.
[500] Taunton and Somerset Restated Services Agreement (n494) Clause 6.

research collaboration agreement between Google Health and Moorfields Eye Hospital NHS Foundation Trust, Clause 2.1 under the 'Fees and Financial Contributions' section is also redacted.[501]

These contractual agreements share a common feature; that clauses relating to payment and the costs of Google's services have been redacted under commercial confidentiality requirements. This prevents the public from accessing information about the price of the company's technologies and their long-term costs to the NHS.

In an interview with Digital Health magazine in March 2017, DeepMind co-founder Mustafa Suleyman suggested that prices would "default to market rate" after initial contracts with NHS trusts end.[502] In the same interview, as well as the Independent Review Panel's 2018 report, the possibility of an outcome-based payment model was also posited as a potential future pricing model.[503] Despite these vague statements, the price Google Health UK will charge NHS trusts for access to its technological innovations ultimately remains unclear.

In light of Google Health's exclusive rights to all developed IP under the partnership, this lack of clarity and transparency around pricing has problematic implications for access to these technologies in the NHS. In the pharmaceutical sector, time-limited monopoly rights over new drugs have enabled pharmaceutical companies to raise the prices of medicines to levels that are unaffordable to resource-scarce health systems, preventing vulnerable patients in developing countries from accessing medicines they need. The case of Myriad Genetics

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[501] Moorfields Eye Hospital Restated Research Collaboration Agreement (n495) Clause 2.1.
[502] Laura Stevens 'Big Read: What does Google DeepMind want with the NHS?' (*Digital Health,* 20 March 2017) <www.digitalhealth.net/2017/03/deepmind-mustafa-suleyman-interview/> accessed 10 August 2020; 'DeepMind Health Independent Review Panel Annual Report' (15 June 2018) (report no longer available online- pdf available from author), 11.
[503] Ibid.

exemplifies this risk; the company was granted monopoly rights over diagnostic testing kits for breast cancer, enabling it to inflate their price and restrict access, even to some of those women involved in the original research to develop them.[504] By similarly granting Google Health an intellectual monopoly on developed IP without delineating clear conditions relating to future pricing, DeepMind-NHS risks corporate price-gouging that renders any technological innovation unaffordable to some- if not all- NHS trusts.

I raised the question of access in my interview with the Wellcome Collection's Natalie Banner, who explored one hypothetical scenario:

"One of the challenges we have is that if you have companies like DeepMind going into NHS trusts... let's say they are developing a machine learning algorithm for a particular function, right? That is incredibly valuable because they're training it on real patient data. As messy as that is, they are training something that can then work in other contexts. They can then offer that service for free or for a reduced price for a certain length of time to that NHS trust. They can then go to a different NHS trust and charge them full price."

Her response highlights the potential for Google Health UK to charge differential, inflated prices that are unaffordable to NHS trusts with greater resource constraints. It draws attention to the inequitable impacts of fragmentation in the health service- the direct result of decades of neoliberal reforms since the 1980s- and the resulting 'innovation lottery' in the NHS, in which avoidable variation in

[504] Parry & Greenhoulgh (n68).

access to new technologies prevents optimal health outcomes.[505] This inequity in access to technologies is particularly problematic in light of the correlation between financial performance and quality of care in NHS trusts, as patients in greatest need of health improvements through new technological innovations are least likely to benefit from them.[506]

The risks that price-gouging poses to equitable access to Google Health's technologies in the NHS are further exacerbated by the issue of digital maturity. Digital maturity refers to "how well... providers... are making use of digital technology to achieve a health and care system that is paper-free at the point of care".[507] Data collected by NHS England reveals significant variation in the digital maturity of NHS trusts;[508] this impacts their ability to adopt new algorithmic technologies, which rely on well-functioning digital infrastructure and relevant technical expertise.[509]

This problematic relationship between digital maturity and equitable access to technologies was reflected in my interview with Professor Julian Huppert, in which I questioned how DeepMind Health had selected which NHS Trusts to work with:

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[505] Chris Thomas et al 'The Innovation Lottery: Upgrading the Spread of Innovation in the NHS' (Institute for Public Policy Research, June 2020) <www.ippr.org/files/2020-06/the-innovation-lottery-june20.pdf> accessed 18 September 2020.
[506] See Myura Nagendran et al 'Financial performance of English NHS trusts and variation in clinical outcomes: a longitudinal observational study' (2019) BMJ Open 9(1) <https://bmjopen.bmj.com/content/bmjopen/9/1/e021854.full.pdf> accessed 21 September 2020; Parry & Greenhoulgh (n68).
[507] NHS England, 'Digital Maturity Assessment' available at < https://www.england.nhs.uk/digitaltechnology/connecteddigitalsystems/maturity-index/ > (accessed 21 June 2021).
[508] See NHS England '2015/16 Digital Maturity Assessment Baseline' </www.england.nhs.uk/digitaltechnology/wp-content/uploads/sites/31/2016/04/dma-scatter-plot-infrastructure.pdf> accessed 18 September 2020.
[509] Deloitte Centre for Health Solutions 'Closing the digital gap: Shaping the future of UK healthcare' (June 2019) <www2.deloitte.com/content/dam/Deloitte/uk/Documents/life-sciences-health-care/deloitte-uk-life-sciences-health-care-closing-the-digital-gap.pdf> accessed 18 September 2020, 1.

"Within the UK, if we park the rest of the world where this information is different, a lot of it is about which hospitals are up for doing it. The main capacity constraint is on the hospital side. Do the hospitals have- I'm talking Streams only here- do the hospitals have a project management team- it doesn't need to be their own people- who could implement it. At the moment, they're only doing it in places that want to do it. Now, that's not perfectly equitable of course. More dynamic hospitals are, in general, better. But if you're piloting, there's no point in piloting a new project with a bunch of people who don't want to have it; they won't use it. We know that."

His response highlights how an NHS trust's readiness and capabilities- both key indicators of digital maturity-[510] are critical precursors to partnership with the company. This is further evidenced by DeepMind Health's choice of NHS partners to date, which are predominantly research-focused, university-linked hospitals or NHS Global Digital Exemplars.[511] The importance of digital maturity in the establishment of data-driven research partnerships thus illustrates how these collaborations may generate new inequities in the NHS in the form of digital divides between the 'Big Data rich' and 'Big Data poor'.[512]

These findings suggest that the lack of assurances surrounding the future pricing of Google Health's technologies fails to prevent the possibility of corporate price-gouging that results in inequitable access to the health benefits of the

[510] NHS England 'Digital Maturity Assessment' <www.england.nhs.uk/digitaltechnology/connecteddigitalsystems/maturity-index/> accessed 18 August 2020.
[511] Global Digital Exemplars are digitally mature NHS trusts that receive additional funding from NHSX to become high-performing, world-leading technological innovators. The Royal Free Hospital NHS Foundation Trust, Imperial College Healthcare NHS Trust, and Taunton and Somerset NHS Foundation Trust are among the list of 17 Global Digital Exemplars. See NHS England, 'Acute Global Digital Exemplars' <www.england.nhs.uk/digitaltechnology/connecteddigitalsystems/exemplars/acute-global-digital-exemplars/> accessed 18 August 2020.
[512] danah boyd & Kate Crawford 'Critical questions for big data: Provocations for a cultural, technological, and scholarly phenomenon' (2012) Inf Commun Soc 15(5) 662-679.

collaboration. They demonstrate how- where due consideration is not given to the context of the health systems in which they are embedded- data-driven research partnerships like DeepMind-NHS may contribute towards rather than mitigate inequity in health systems, echoing criticisms of other forms of PPP like GHPs and PPPs in pharmaceutical innovation.[513] They further give weight to right to health scholars' views that emerging technologies raise concerns around accessibility and availability and the exacerbation of digital divides.[514]

These findings also highlight the ways in which neoliberal reform in the NHS- which has simultaneously fragmented the system and propagated partnerships with commercial actors to deliver health goods and services- generates health inequity. This inequity is further exacerbated by the need for digital maturity as a precondition to engaging in data-driven research partnerships with technology companies, revealing the emergence of novel forms of health systems inequity in the digital age. Together, these findings have significant implications for equitable access to healthcare under the right to health.

4.2.3. The resource trade-off: benefits for whom?

My analysis thus far highlights how, despite claims that the DeepMind-NHS partnership will deliver mutual benefits, the contractual agreements that form the legal basis of the collaboration give Google Health exclusive rights to all developed IP and its scientific and commercial benefits, and with it the power to restrict NHS patients' access to any resulting health technologies. These asymmetries in the

[513] Clark & McGoey (n54); Ruckert & Labonté, (n54); Mazzucato et al (n208); Pratt & Loff (n54).
[514] Sun (n98).

distribution of resources under DeepMind-NHS call into question the incentives driving NHS trusts to enter into agreements that appear to disproportionately benefit Google Health.

One significant finding arising from my analysis is the promise of access to technology for free. Through a Freedom of Information (FOI) request, one journalist at The Register determined that the Royal Free and other NHS trusts using Streams are able to access the application for free for the duration of their initial contract with the company, provided their costs do not exceed £15,000 a month.[515] The company's AI research partnerships appear to follow a similar pattern; under the Moorfields collaboration, the trust's hospitals have free access to any resulting algorithms and technological innovations for the five-year duration of the initial contract.[516]

In our interview, Dr Tamar Sharon explained how this offer of technology for free obscures the real deal underlying data-driven research partnerships:

"We hand over these publicly-funded datasets for companies to use to feed into AI because machine learning needs a lot of data to train it. The business model is not that Google would sell this data- which is its business model in advertising- but that it develops new services that it then sells back to the public sector. We give away this data and- further down the line- we'll have to pay for these services. That will be at a cost again."

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[515] SA Mathieson 'Pssst... Wanna Participate In A Google Deepmind AI Pilot? Be Careful' (*The Register*, 2017) <www.theregister.co.uk/2017/08/23/nhs_google_deepmind_lessons/> accessed 10 August 2020.

[516] Mustafa Suleyman 'A major milestone for the treatment of eye disease' (*DeepMind Blog*, 13 August 2018) <https://deepmind.com/blog/article/moorfields-major-milestone> accessed 15 September 2020.

Her comment reveals how patients inadvertently pay for both the development and deployment of Google Health's technological innovations, first through their commercially-valuable data and then with NHS funding to gain access to the end product.

Javier Ruiz of the Open Rights Group elaborated on this point in our interview, drawing comparisons with the Google Books partnership:

"Going back to the question of cost- the investment- part of the problem here is the way this is framed. It's very, very similar to the whole debate with archives, libraries, digitisation and public-private partnerships. The main incentive is for hospitals not to have to invest so they are lured in. For a public organisation not to have to put money aside and to have someone doing it for free in exchange for some future cost- it's very, very tempting. We've seen it in other sectors and it's very, very hard to stop the power of free.

Should we force an NHS manager to say, "Sorry, no, you cannot do a free deal with DeepMind. You have to now find millions and put out a tender and then find some companies and now pay DeepMind or IBM or whoever for what they are doing"? Because of the way that public sector finance works, it's tricky.

I mean, they're presented as having no cost to the public. They definitely have long term costs and the longer-term costs can be a lot higher. The theory is that when people sign this kind of partnership, they get an idea of what the value for money is and that they're getting a fair exchange. The reality is that, as long as it's free, they just don't care."

His concerns were echoed by Vivek Kotetcha, Research Manager at the Centre for Health and the Public Interest, who highlighted the political appeal of this 'credit card approach' to spending for trusts wishing to 'get something for nothing'.

Together, these findings highlight how the short-term incentive of access to technology for free can overshadow consideration of the long-term costs and broader implications of research collaborations like DeepMind-NHS for public sector healthcare providers. In light of the controversial history of public-private partnerships in the NHS- in which the manipulation of value appraisal procedures has facilitated corporate wealth extraction-[517] and evidence that many PPPs fail to achieve their purported benefits, this lack of accurate and transparent appraisal is problematic.[518]

These findings also draw attention to the novel 'data extractivist' model through which technology companies like Google Health are able to capture value through PPP.[519] In exchange for the promise of technology for free, NHS trusts that provide technology companies with free access to patient data inadvertently end up 'paying twice'; with both their patients' data- which has scientific, technological and commercial value- and their precious funds.[520] The DeepMind-NHS partnership thus facilitates a process of 'data rentiership', which enables technology companies "to capture or extract value through ownership and control of data as an asset".[521]

Together, these findings uncover the real resource trade-off underlying DeepMind-NHS; that beneath the rhetoric of mutual benefit and the promise of time-

[517] Shaoul 'A critical financial analysis of the Private Finance Initiative: selecting a financing method or allocating economic wealth?' (n50).
[518] Brinkerhoff & Brinkerhoff (n39).
[519] Morozov (n63).
[520] Ebeling (n72); Mazzucato & Roy (n221).
[521] Birch et al (n40) 3.

limited access to technology for free is a partnership model that allocates the long-term scientific and commercial benefits- as well as the power to control access to their health applications- solely to Google Health. It demonstrates how- much like in other PPP models- the notion of value in data-driven research partnerships can be construed in ways that serve commercial over public interests.[522] The issue of value appraisal is further complexified in such partnerships by the ambiguity and ethical pluralism surrounding this terminology in the context of data-driven innovation.[523] This resource trade-off underlying DeepMind-NHS calls into question the UK government's socioeconomic rights obligations in data-driven research partnerships, demonstrating that more is at stake in data-driven research partnerships than patient privacy alone.

4.3. Knowledge Asymmetries

4.3.1. Public sector secrecy: the lack of transparency surrounding DeepMind-NHS

In November 2016, the initial partnership between DeepMind Health and the Royal Free NHS Foundation Trust was first publicly announced on DeepMind's website.[524] This announcement of the collaboration was made an entire year after the data transfer had commenced in November 2015 and at least six months after

[522] Mazzucato (n65); Shaoul 'A critical financial analysis of the Private Finance Initiative: selecting a financing method or allocating economic wealth?' (n50).
[523] Sharon 'When digital health meets digital capitalism...' (n41).
[524] Mustafa Suleyman, 'Working with the NHS to build lifesaving technology' (2016) available at < https://deepmind.com/blog/announcements/working-nhs-build-lifesaving-technology > (accessed 21 June 2021)

Hodson's New Scientist article exposed its controversial impacts on patient privacy.[525]

Despite the eventual public announcement of the Streams collaboration, DeepMind Health had always intended the scope of its partnership with the NHS to be significantly more wide-ranging. The Memorandum of Understanding between DeepMind and the Royal Free states the parties' intention to establish a "wide-ranging collaborative relationship for the purposes of advancing knowledge in the fields of engineering and life and medical sciences through research and associated enterprise activities".[526] In Clause 4.3, both parties recognise that the collaboration "may involve a number of project-related transactions", and Clause 5.1 goes on to list numerous potential areas of future collaboration beyond the scope of the Streams project, including bed and demand management, financial control products, reading of medical images, task management and junior doctor deployment, and more.[527] Furthermore, in a public engagement event in November 2016, DeepMind co-founder Mustafa Suleyman disclosed the company's ambition to develop a multipurpose, patient-centred collaboration platform for clinical use in the NHS and a patient portal to make this data directly available to patients; these are significantly more grandiose plans than those made available to the public on the company's website.[528] These findings highlight how, as early as January 2016, both parties had far greater ambitions for the collaboration than the Streams project alone. They

[525] Hodson (n11).
[526] Royal Free London NHS Foundation Trust, 'Memorandum of Understanding' (2016) available at < https://drive.google.com/file/d/0BwQ4esYYFC04anR4VHM3aXZpMTQ/view?resourcekey=0-6JC04imLtPq9mpfusBNiug > (accessed 21 June 2020), Clause 3.4.
[527] Ibid, Clause 4.3 and 5.1.
[528] DeepMind, 'DeepMind Health - Patient and Public Engagement Event' (20 September 2016) available at < https://www.youtube.com/watch?v=wBfBiD38x34 > (accessed 21 June 2021).

support Hodson's suggestion that DeepMind-NHS "goes far beyond what has been publicly announced".[529]

Sam Smith of MedConfidential drew attention to Hodson's critical role in uncovering the details of the deal:

"Why did the DeepMind-Royal Free deal get away with the things they got away with? Because they thought they could... It's only through Hal's work in requesting the contract- i.e. one journalist asked a question- that this came out. What people get upset about is the consequence of people using this secrecy. Basically, get rid of the secrecy!"

His comment implies that, without Hodson's investigative work, the data transfer may have remained undisclosed to the public, highlighting the critical role of the media in exposing privacy breaches by public actors.

Describing his investigation, Hodson explained that the Royal Free deal provided an unusual opportunity to gain insight into DeepMind's work:

"This was the first opportunity that I had seen to have a public surface area for freedom of information requests because, normally, DeepMind's not going to give you their contracts with private businesses. The hospital has to give you the contracts barring certain restrictions"

Furthermore, under the MOU between DeepMind and the Royal Free, the company committed to assisting and cooperating with the trust to fulfil its disclosure

[529] Hodson (n11).

obligations under the FOIA.[530] This highlights how public-private partnerships like DeepMind-NHS may provide an opportunity to gain access to what is usually confidential information surrounding commercial operations, providing weight to the view that PPPs in health can facilitate greater transparency.[531]

However, the journalist went on to describe the complex nature of the information he uncovered:

"It was quite interpretive because the data sharing agreement is not the database- it's just the contract that governs that sharing of the database- so there was quite a lot of just figuring out data protection law in order to figure out what they were talking about and figuring out NHS lingo for HL 7 and Fire APIs and all that kind of stuff."

His observation suggests that, even where mechanisms to facilitate transparency exist, they may continue to obscure corporate misconduct through their complexity, highlighting the importance of meaningful transparency.[532]

Further to this, the use of commercial confidentiality laws acted as a barrier to disclosure of the commercial details of the partnership. In a proceeding section of this chapter, I highlighted how sections relating to pricing and costs in the publicly-available contractual agreements between Google Health and the NHS have been redacted. In our interview, Eleonora Harwich, Head of Digital and Tech Innovation at Reform, questioned why clauses relating to the exchange of money had been left blank in the company's published contracts. Another interviewee drew attention to tech companies' use of non-disclosure agreements, stating that these companies

[530] Ibid.
[531] Hood et al (n55); Reich (n59).
[532] Pasquale (n71).

"aren't going to stop people signing NDAs- but I think they should because it holds back the public debate about what we want". This illustrates how- even where transparency mechanisms exist- the use of corporate confidentiality laws enables technology companies to prevent the disclosure of critical information necessary to assess the value and cost-effectiveness of partnerships like DeepMind-NHS.[533]

Some interviewees suggested that the DeepMind-NHS collaboration sheds light on a more systemic lack of public sector transparency surrounding commercial deals in the NHS. The Wellcome Trust's Dr Natalie Banner commented:

"There are a lot of commercial partnerships already in the NHS. You don't necessarily talk about them, but they do exist. One of the most telling things that came out of that situation was- I think it was the press officer for the Royal Free- who said, "we've got 1500 of these sorts of agreements. We don't really see what the problem is." That was just horrifying, right? The idea that you've got these agreements going on all over the place, because we don't tend to talk about commercial involvement in the NHS very much."

Annemarie Naylor of Future Care Capital similarly described the difficulties of trying to obtain information about commercial deals with technology companies in the NHS. Their comments echo political economists' frustrations at the 'democratic accountability deficit' surrounding PFI projects,[534] in which uncovering even basic data about the number, size and cost of PFI deals was problematic.[535] They also

[533] Hood et al (n55); Flinders (n55); McGoey (n56).
[534] Hood et al (n55).
[535] Shaoul 'The Private Finance Initiative or the public funding of private profit?' (n50) 194.

highlight the lack of oversight of commercial technology partnerships like DeepMind-NHS, which has proven a barrier to effective accountability in other forms of PPP.[536]

Together, these findings suggest that the DeepMind-NHS partnership has suffered from a lack of transparency that both obscured the details of the original data transfer- enabling a serious privacy breach that was unbeknownst to the public- as well as the commercial aspects of the collaboration, preventing accurate public assessment of its long-term risks and benefits. This is problematic in light of the view that openness is fundamentally important in establishing public trust in data-driven research and PPPs more generally.[537] These findings suggest that- despite their potential to facilitate greater access to information- data-driven research partnerships may fail to advance good governance norms like transparency in practice.[538] Given the critical importance of transparency to accountability for the right to health in international law, these findings imply that data-driven research partnerships like DeepMind-NHS have significant implications for the right to health.

4.3.2. The 'Googlization' of DeepMind Health

4.3.2.1. The DeepMind-Google relationship

Throughout the course of my research, it became evident that DeepMind's close relationship to Google had been the source of much of the public controversy surrounding DeepMind-NHS. This is encapsulated in the following comment from one anonymous interviewee:

[536] Hood et al (n55); Brown (n57); Hodge (n57).
[537] Blasimme et al (n70); Hood et al (n55).
[538] Brinkerhoff & Brinkerhoff (n39).

"This whole fuss has been made because it is Google. That is one thing we really need to understand. There is a concern about data sharing and there is a concern about how the agreement was drawn up but one thing I can tell you- if it was not Google, there would not have been this much of an uproar."

Another interview participant consolidated and elaborated upon this view:

"People immediately react quite viscerally to the idea of Google or Amazon having access to healthcare data. The important word there is 'visceral'; there's a very emotive problem with that."

These insights reveal widespread public concerns about the power and trustworthiness of Big Tech and their expansion into healthcare markets.

DeepMind's proximity to Google had troubled critics from the start of the DeepMind-NHS collaboration. Multiple interviewees highlighted that the original ISA with the Royal Free was signed by Google, not DeepMind, raising questions about the degree of separation between the two. In our interview, Professor Julian Huppert- at the time Head of DeepMind's IRP- expressed concerns about the companies' close relationship:

"I think how DeepMind Health show their clear separation from Google is a very big issue. They are very careful to do that internally. Do people believe that is a big problem? One of my concerns is what happens if somebody else comes in and runs DeepMind Health? What is tied down legally and what is a good person saying good

things and then the next person comes and says, "okay, well I have a different view on the world. I'm going to do it like this". I think there are some real issues around how you solidify that."

Huppert's comments were also reflected in the IRP's 2018 annual report, which recommended that DeepMind make efforts to robustly entrench their separation from Google.[539]

Despite this, for some time, DeepMind remained secretive about the business model it intended to pursue under its partnership with the NHS. This issue was raised by Javier Ruiz in our interview:

"The biggest problem here is that DeepMind- even with all their efforts at discussing ethics and asking all these big questions- they're not really explaining what their business model is. That might be ok back when Google appeared but now, in 2018, I don't think you can have a technology company that doesn't explain what their potential business model is. The precautionary principle right now should be that if you cannot explain your business model, we have to assume you're going to be the worst case. We need to assume that their business model is going to be to capture public health processes that- at the moment- are open."

His concerns were also reflected in DeepMind's 2018 Independent Review Panel report, which encouraged the company to be more transparent to reassure the

[539] DeepMind Health Independent Review Panel Report (n502).

public their revenue was coming from a legitimate source and quash suspicions they had perverse motives.[540]

In my interview with Dr Tamar Sharon, she explained the implications of this opacity:

"The business models aren't very clear, who is profiting and how exactly is not at all clear."

Further to this, DeepMind Health had made a concerted effort to distance itself publicly from Google; the company avoided using Google's branding to promote its own work and publicly claimed that "data will never be connected to Google accounts or services or used for any commercial purposes like advertising or insurance".[541]

4.3.2.2. The Google takeover

The Google conglomerate is a 'de facto' monopoly with enormous market power;[542] Alphabet's annual revenues would make it the 59th wealthiest state in the world by gross domestic product (GDP) were it a country.[543] This concentration of market power has been facilitated by the acquisition of corporate competitors, on

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[540] Ibid.
[541] Chris Stokel-Walker 'Why Google consuming DeepMind Health is scaring privacy experts' (*Wired*, 14 November 2018) <www.wired.co.uk/article/google-deepmind-nhs-health-data> accessed 10 August 2020.
[542] Mazzucato (n65) 218.
[543] Fernando Belinchòn & Ruqayyah Moynihan '25 Giant Companies That Are Bigger Than Entire Countries' (*Business Insider España*, 25 July 2018) <www.businessinsider.com/25-giant-companies-that-earn-more-than-entire-countries-2018-7?r=US&IR=T> accessed 10 August 2020.

which Google and Alphabet have jointly spent tens of billions of dollars over the past two decades.[544]

One interviewee discussed the implications of this venture capital (VC) culture for the DeepMind-NHS partnership:

"Anon: We all think we're supporting the small fish to fight against the big companies when, actually, the VC funding model for start-up companies goes something like this. "I have a model. Here's $5 million. In the next year, I want you to make that model the most effective possible". They go and find data, make an effective model, and then you get to exit time and the exit strategy for most start-ups- 95 to 99% of them- is to sell to a big company.

A: Like DeepMind?

Anon: Exactly. We think we are creating competition by supporting smaller start-ups but actually the start-ups will all get acquired by the big companies. We're ending up with an aggregation of all the IP- the IP from the NHS, the IP from the machine learning algorithms- all going into these four or five companies across the world. That's kind of scared me in the first instance."

Their insights highlight how Big Tech utilise mergers and acquisitions to quash competition and capture IP. The result of this, one interviewee suggested, is

[544] Matt Reynolds 'If you can't build it, buy it: Google's biggest acquisitions mapped' (*Wired*, 25 November 2017) <www.wired.co.uk/article/google-acquisitions-data-visualisation-infoporn-waze-youtube-android> accessed 10 August 2020.

the concentration of power in the hands of "*a very select group of white, middle-class men in Silicon Valley*".

During the course of my research, this culture of strategic mergers and acquisitions played out. In November 2018, DeepMind made the shock announcement that the DeepMind Health unit would be subsumed under Google Health.[545] This required the transfer of all contracts between the NHS and DeepMind to Google Health; all partnering NHS trusts- excluding Yeovil District Hospital NHS Foundation Trust- subsequently completed this transfer of contracts.[546] DeepMind justified the merger on the basis of commercial interests, claiming it would provide the opportunity to scale-up the company's technologies and bring them to the wider world.[547]

In one interview- which took place soon after the merger- the participant reflected upon the legitimacy of these justifications:

"The sad truth... is that I think even DeepMind are on borrowed time to a certain extent. I don't know the details of the Streams move but I suspect that was guided by commercial considerations. The point is that DeepMind don't have the know-how to commercially scale-up Streams and that's why Google took it on."

Their comment highlights that- despite suggestions to the contrary- DeepMind remains a commercial venture subject to corresponding incentives, pressures and

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[545] Dominic King, 'DeepMind's health team joins Google Health' (*DeepMind blog*, 18 September 2019) < https://deepmind.com/blog/announcements/deepmind-health-joins-google-health > accessed 11 July 2021).
[546] Owen Hughes 'Google Health ties up data agreements with NHS trusts' (*Digital Health*, 20 September 2019) <www.digitalhealth.net/2019/09/google-health-ties-up-data-agreements-with-nhs-trusts/> accessed 10 August 2020.
[547] Demis Hassabis et al 'Scaling Streams With Google' (*DeepMind blog*, 13 November 2018) <https://deepmind.com/blog/announcements/scaling-streams-google> accessed 10 August 2020.

shareholder interests. This underscores the need to scrutinise technology companies as commercial actors and not simply 'forces for good'.[548]

The merger also saw the abandonment of the IRP, which DeepMind suggested was "unlikely to be the right structure for the future" given the company's global expansion.[549] One interviewee expressed disappointment at the decision:

"The real shame is that the panel is now being wound down with the movement of Streams to Google. I've said this publicly- I think that's a bad development. I really regret that that is the decision they've taken and I hope that maybe they're still trying for that decision to be reversed."

The merger exemplifies how the 'Googlization' of health is facilitated by research partnerships like DeepMind-NHS, which enable Big Tech to further expand their monopoly powers into the health sector.

One interviewee contemplated the future of this expansion into healthcare markets:

"I think the longer-term thing is going to be people wearing sensors and interacting with applications and you see that in the approach that Amazon and Google are taking. They're starting to build direct customer services, where basically you wear your sensors, they hold that information forever- you can't get that back."

[548] Vaidhyanathan (n73).
[549] Parmy Olson 'Google Quietly Disbanded Another AI Review Board Following Disagreements' (*The Wall Street Journal*, 16 April 2019) <www.wsj.com/articles/google-quietly-disbanded-another-ai-review-board-following-disagreements-11555250401> accessed 11 August 2020.

This view is supported by Google's acquisition of Fitbit in 2018 for $2.1 billion,[550] cementing the company's intention to capture the wearables market and further expanding its powers of surveillance and profitability.[551]

Technology companies like Google also have a competitive advantage in developing AI in healthcare. One interviewee explained the source of this first-mover advantage:

"The reason why they have these monopolies is because they have the data. These are the five companies that have just so much data that whatever machine learning techniques they build are just going to be better and it'll be really hard to compete."

Their comment highlights how companies like Google benefit from the network effects of digital markets which- in combination with increasing returns to scale- amplify their monopolistic effects, "placing an enormous concentration of market power in the hands of a few firms".[552]

Javier Ruiz, Policy Director at Open Rights Group, expressed concern that this first-mover advantage might position the company to shape NHS information technology (IT) systems to fit its own needs, a fear shared by Head of DeepMind's former IRP, Professor Julian Huppert:

"I would be very concerned- and this is something we pushed in the last report and we kept going on about- if DeepMind Health's approach was to do with lock in... A

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[550] David Phelan 'Google Buys Fitbit For $2.1 Billion: Here's What It Means' (*Forbes*, 1 November 2019) <www.forbes.com/sites/davidphelan/2019/11/01/google-buys-fitbit-for-21-billion-heres-what-it-means/#13ab9e8f732f> accessed 10 August 2020.
[551] Lupton (n334); Sharon (n334).
[552] Mazzucato (n65) 218.

very standard tech approach is we set up a system, we charge you a lot, and then we make it very hard for you to change to somebody else. I would be extremely alarmed if that was how things went. There's a big difference between saying we will provide you with a thing and it's really good but if you want to have someone else provide you with a thing, you can; you stay with us if we're the best and the cheapest. That I have no problem with and I think it would be odd to say the private sector can't ever offer that. Lock in- completely different."

His comments echo Powles and Hodson's warning that this first-mover advantage might enable Google to gain an "entrenched market position" in the NHS.[553]

Thus, by enabling Google's takeover of DeepMind Health and the company's stealthy expansion into healthcare markets, DeepMind-NHS risks affording the company ever more expansive powers to "build, own and control networks of knowledge about disease".[554] The lack of transparency surrounding DeepMind's close relationship to Google exemplifies how technology companies have "deployed strategies of obfuscation and secrecy to consolidate power and wealth".[555]

4.3.2.3. Google's lack of accountability

Concerns about Google's encroachment on healthcare markets has been fuelled by the company's disregard for privacy norms and seeming lack of legal accountability. Alongside the other major platform monopolies, the privacy implications of Google's business model- which relies on controversial mass data

[553] Powles & Hodson (n2) 363.
[554] Powles & Hodson (n2) 364.
[555] Pasquale (n71) 14.

collection and analysis and surveillance practices- have been heavily criticised by civil society organisations like Amnesty International and Human Rights Watch and United Nations mechanisms like the Special Procedures.[556] This business model of 'surveillance capitalism',[557] as Zuboff has argued, is characterized by economic imperatives that "disregard social norms and nullify the elemental rights associated with individual autonomy that are essential to the very possibility of a democratic society".[558]

Criticism of Google's business model has been further fuelled by the company's implication in numerous privacy scandals over the past decade. These include high-profile data breaches and privacy concerns surrounding the company's various tools and applications, including its search engine, Gmail, and Google Streetview.[559] Some of the company's controversial practices have been successfully challenged by data protection authorities; in France, for example, Google was fined 50 million euros for failing to properly disclose to users how data is collected across its services to show personalized advertisements.[560] However, other cases- including so-called Project Nightingale, a partnership agreement with private

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[556] Amnesty International, 'Surveillance Giants: How the business model of Google and Facebook threatens human rights' (2019) available at < https://www.amnesty.org/download/Documents/POL3014042019ENGLISH.PDF > (accessed 21 June 2021); Deborah Brown, 'Big Tech's Heavy Hand Around the Globe' (2020, Human Rights Watch) available at < https://www.hrw.org/news/2020/09/08/big-techs-heavy-hand-around-globe > (accessed 21 June 2021); UNGA 'The right to privacy in the digital age: Report of the United Nations High Commissioner for Human Rights' (2018) A/HRC/39/29.

[557] Zuboff (n63).

[558] Zuboff (n63) chap 1 sec III.

[559] Kate O'Flaherty, 'New Warning Reveals Gmail's Major Privacy Problem' (2019, Forbes) available at < https://www.forbes.com/sites/kateoflahertyuk/2019/06/27/new-warning-reveals-gmails-major-privacy-problem/?sh=6fc29eb97d34 > (accessed 21 June 2021); BBC News, 'Google ranked 'worst' on privacy' (2007, BBC News) available at < http://news.bbc.co.uk/1/hi/technology/6740075.stm > (accessed 21 June 2021); Sam Knight, 'All seeing Google Street View prompts privacy fears' (2007, The Times) available at < https://www.thetimes.co.uk/article/all-seeing-google-street-view-prompts-privacy-fears-t6m0th6sqv3 > (accessed 21 June 2021).

[560] Adam Satariano, 'Google is Fined $57 Million Under Europe's Data Privacy Law' (2019, New York Times) available at < https://www.nytimes.com/2019/01/21/technology/google-europe-gdpr-fine.html > (accessed 21 June 2021).

US healthcare provider Ascension in which Google secretly gained access to tens of millions of identifiable patient records without patients' knowledge or consent-[561] fall within the bounds of legality despite their unscrupulous nature. The Ascension story is reminiscent of DeepMind's exploitation of ambiguities in the data controller/ processor distinction in the DeepMind-NHS case, highlighting how disparities between legal and ethical categories have left the public with limited means to hold technology companies to account for intrusive data practices.

Further to this, in recent years, Google has received multiple multibillion-dollar fines for violating anti-trust legislation.[562] The company has also faced numerous accusations of tax evasion; for example, in 2017, Reuters reported it had illegally shifted $23 billion to a tax haven in Bermuda in an effort to reduce its overseas tax bill.[563] In our interview, Eleonora Harwich drew attention to the inequity of Google's purported tax evasion in the context of DeepMind's collaboration with the NHS:

"What is disturbing is that DeepMind are part of Alphabet and Alphabet doesn't pay tax. To me, when you talk about making sure that these partnerships actually benefit society, that is an extremely unfair thing. If you think about any other company in the UK, you could still abide by the rationale of "okay, they provide jobs, they pay tax here", so they're already giving back that benefit on top of improved health outcomes. Some people might actually argue, "why would you do a revenue sharing

[561] Heidi Ledford 'Google health-data scandal spooks researchers' (*Nature*, 19 November 2019) <www.nature.com/articles/d41586-019-03574-5> accessed 15 September 2020.
[562] James Vincent 'Google Hit With €1.5 Billion Antitrust Fine By EU' (*The Verge*, 20 March 2019) <www.theverge.com/2019/3/20/18270891/google-eu-antitrust-fine-adsense-advertising> accessed 10 August 2020; James Vincent 'Google fined a record €2.4 billion by the EU for manipulating search results' (*The Verge*, 27 June 2017) <www.theverge.com/2017/6/27/15872354/google-eu-fine-antitrust-shopping> accessed 31 August 2020.
[563] Reuters 'Google Shifted $23Bn To Tax Haven Bermuda In 2017, Filing Shows' (*The Guardian*, 3 January 2019) <www.theguardian.com/technology/2019/jan/03/google-tax-haven-bermuda-netherlands> accessed 10 August 2020.

agreement, if you're already taxing them". But when you talk about the DeepMind case, it's just like, "well, they actually don't pay their taxes". Or, at least, Alphabet doesn't."

Considering the critical role that public investment has played in Google's success- the company's original search engine algorithm was supported by a grant from the National Science Foundation-[564] these accusations of tax evasion are particularly scandalous. Google's seeming disregard for the law demonstrates how the company is "not being subject to democratic control and public accountability in the same manner as public actors".[565]

Another common concern among interviewees was the increasingly prominent role that both DeepMind and Google occupy in data-driven technology policymaking circles. One interviewee commented on the privileged position technology companies like Google enjoy in regulatory debates around AI:

"In the case of AI, what I find really concerning is that- and this doesn't hold for all regulators because some are very technically savvy- that they tend to naturally see industry as the right partner to have at the table. I can assume that it has something to do with the fact that these are the companies that are driving the field. These are the companies that have the data. These are the companies that are building the infrastructure needed to do effective machine learning techniques. So these companies are naturally invited to come and then academics are invited, and then the rest of us are all an afterthought- civil society organisations, human rights people,

[564] Mazzucato (n39) 12.
[565] Prainsack (n69) 127.

affected communities- they're all not necessarily perceived as experts. That means that whatever shape the regulation takes is going to be influenced heavily by industry needs and industry needs don't always map on to societal values or societal needs. I think this is what the whole DeepMind-NHS kerfuffle showed."

Another participant emphasised the need to engage commercial actors in regulatory debates but concurred that the government was heavily influenced by Big Tech:

"You can't make good public policy without some engagement with industry because you just don't know how it works so you'll never get the practicalities rights. You've got to have some. It's clearly much easier for big companies to get the ear of government and I think it's inherently quite hard to know how to counter that influence."

One interviewee drew comparison between Big Tech and other powerful corporate lobbies:

"The biggest lobbyers of government in the modern day are no longer Big Oil or Big Tobacco- it's Big Data."

These findings support Powles and Hodson's argument that Big Tech "are already in key positions in policy discussions on standards and digital reform".[566] This level of influence is problematic in the context of corporate bias in PPPs, as it

[566] Powles & Hodson (n2) 357.

risks enabling companies to evade responsibility and expand corporate interests into the public domain.[567]

Further to this, both DeepMind and Google's influence extends far beyond policymaking; my analysis reveals the companies have also made significant investments in academic and public research institutions. In 2017 alone, the company spent £8.1 million on academic donations, including grants to New York University, University College London, Imperial College London and the University of Alberta.[568] They are also supporting research at the Universities of Cambridge and Oxford; in 2018, they gave Cambridge an 'undisclosed sum' to appoint a DeepMind Chair of Machine Learning and support a number of master's students.[569] Beyond funding technical research in machine learning, the company has also provided support to the Oxford Internet Institute, which conducts research on AI ethics and regulation; this conflict of interest has led to criticism of some of the Institute's academics, who failed to publicly declare the company's financial backing in their publications.[570]

Some company employees are also teaching at highly respected universities like Oxford and University College London and are encouraged to openly publish their research in academic journals.[571] DeepMind have even created their own

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[567] Nemitz (n72) Shaoul 'The Private Finance Initiative or the public funding of private profit?' (n50); Buse & Harmer (n199).
[568] Ghosh (n479).
[569] Sam Shead 'Deepmind Is Giving Cambridge Money To Hire Staff' (*Forbes*, 25 July 2018) <www.forbes.com/sites/samshead/2018/07/25/deepmind-is-giving-cambridge-uni-money-to-hire-staff/> accessed 10 August 2020; 'Cambridge To Appoint Deepmind Chair Of Machine Learning' (24 July 2018) <www.cam.ac.uk/research/news/cambridge-to-appoint-deepmind-chair-of-machine-learning> accessed 10 August 2020.
[570] Oscar Williams 'How Big Tech Funds The Debate On AI Ethics' (*New Statesman*, 6 June 2019) <www.newstatesman.com/science-tech/technology/2019/06/how-big-tech-funds-debate-ai-ethics > accessed 10 August 2020.
[571] Sam Shead 'Oxford And Cambridge Are Losing AI Researchers To Deepmind' (*Business Insider*, 9 Nov 2016) <www.businessinsider.com/oxbridge-ai-researchers-to-deepmind-2016-11?r=UK> accessed 10 August 2020.

internal research branch, DeepMind Ethics and Society, tasked with anticipating, mitigating and addressing the risks of AI,[572] raising questions around in-housing.[573] Parent company Google have also been funding research at universities for over a decade; Oxford University alone is purported to have received more than £17 million from the company.[574]

In our interview, Dr Tamar Sharon explained how Big Tech are able to shape research agendas through partnership in and funding of scientific research:

"These companies' inroads into health and medical research are currently mostly collaborative — partnering with public research institutes who turn to them mostly for their technical expertise in data collection, management and analysis. But they are not just facilitating research, they are also carrying out research themselves, and as they become important actors in research, we should also expect that they will begin to influence research agendas."

Her comment implies that DeepMind and Google's interests in research may ultimately enable these companies to shape research agendas in their own interests.[575] Much like corporate-funded philanthropic foundations- who utilized public-private partnership to manipulate global health research priorities to become 'de facto agenda setters'-[576] these companies may seek to redirect research

[572] 'Safety & Ethics' <https://deepmind.com/safety-and-ethics> accessed 10 August 2020.
[573] James Temperton 'Deepmind's New AI Ethics Unit Is The Company's Next Big Move' (*Wired*, 4 October 2017) <www.wired.co.uk/article/deepmind-ethics-and-society-artificial-intelligence> accessed 10 August 2020.
[574] Williams (n570).
[575] Sharon 'The Googlization of health research...' (n41).
[576] Faubion et al (n59).

agendas towards profitable causes, which are not necessarily aligned with public health needs.[577]

Together, Google's privacy violations, utilisation of regulatory loopholes to evade taxation and anti-trust legislation, and the influential position that both DeepMind and Google occupy in regulatory debates surrounding AI reveal the lack of accountability surrounding large technology companies like Google. One interviewee summarised this succinctly:

"The scary thing is each individual has signed a deal with the devil. What do we do as a nation thinking beyond the current institutionalised model into what happens in the future where we'll retain no control? Because were the government to collect this kind of data on people and analyse and act on it and monetise it and use it to advertise and influence politically, everyone would go mental. Yet supranational, multinational corporations, which are beyond the rule of law, do not act to any democratic standard, can't be voted out, are doing it without any problem."

Their comment speaks to emerging power asymmetries between companies, governments and the general public in the area of data-driven health research.[578]

Furthermore, these findings draw attention to the limitations of regulatory efforts for Big Tech,[579] which render these companies "de facto market regulators against whom public and civil society actors are powerless even when faced with stark ethical misconduct".[580] It suggests that Big Tech have become key political

[577] Clark & McGoey (n52).
[578] Sharon 'The Googlization of health research...' (n41).
[579] Arogyaswamy (n71).
[580] Prainsack (n72) 9.

players in the health domain,[581] exemplifying the growing entanglement of public and private sectors in the health data economy.[582] As the BHR community is currently grappling with the question of how to mitigate the power and unlawful behaviour of commercial actors, international human rights law may have a significant role to play in holding companies like Google publicly accountable.

4.3.2.4. The knowledge trade-off: collaboration with whom, at what cost?

My findings in this section revealed that DeepMind-NHS suffered from a lack of public sector transparency. Furthermore, the partnership enabled controversial technology monolith Google to covertly expand its reach further into healthcare markets, generating concerns about the company's lack of transparency and lack of legal and political accountability. These findings suggest that DeepMind-NHS generates knowledge asymmetries between commercial technology companies, health systems and their patients, supporting the view of critical data scholars and political economists who argue that public-private partnerships are reconfiguring the public-private nexus.[583]

These knowledge asymmetries cast doubt on DeepMind Health's public image as a socially-responsible research organisation and its establishment of voluntary accountability and participatory mechanisms. They reveal that the DeepMind-NHS partnership is characterised by an underlying knowledge trade-off; that collaboration with a seemingly publicly-accountable and socially-responsible

[581] Prainsack (n72).
[582] Prainsack (n40).
[583] Ruckert & Labonté (n54); Prainsack (n69); Sharon 'When digital health meets digital capitalism...' (n41).

technology research organisation obscures the covert expansion of the monopoly powers of controversial technology monolith, Google.

This knowledge trade-off implies that the purported benefits of so-called 'health data entrepreneurism' may necessitate compromising the public accountability of data-driven technological research in health.[584] It further points to the 'toothlessness' of voluntary corporate responsibility- which relies entirely on corporate good will- in the face of shareholder interests,[585] highlighting the importance of remaining critical of the effectiveness of such initiatives and underscoring the need for robust accountability mechanisms.[586] These findings thus have important ramifications for state accountability and corporate responsibility for the right to health under data-driven research partnerships.

4.4. Conclusion

This chapter explored the political economy of DeepMind-NHS. It argued that, despite the seeming potential of DeepMind-NHS to deliver public benefits and facilitate collaboration with a socially-responsible, publicly-accountable research organisation, the underlying political economy of the partnership reveals asymmetries in the distribution of resources and knowledge between the company, the NHS and its patients.

These resource asymmetries arise from Google Health's exclusive rights to all developed IP under the partnership and the lack of clarity around the future price of

[584] Prainsack (n73).
[585] Cath (n73); Vaidhyanathan (n73).
[586] Mittelstadt (n324).

any resulting technologies, which risks corporate price-gouging that restricts access to these technologies and exacerbates the innovation lottery in the NHS. Furthermore, these knowledge asymmetries are the product of the lack of transparency surrounding the partnership, DeepMind Health's merger with Google Health and Google's lack of accountability, as evidenced by the company's privacy violations, utilisation of regulatory loopholes and influential position in regulatory debates surrounding AI.

These asymmetries reveal the real trade-offs underlying data-driven research partnerships like DeepMind-NHS; that beneath the veneer of mutual benefit, all scientific benefits and their applications are rewarded to commercial actors, and behind the promise of collaboration with a socially-responsible, publicly-accountable research organisations lies the covert expansion of the powers of Big Tech. These findings have significant implications for the realisation of the right to health in data-driven research partnerships like DeepMind-NHS.

Chapter 5: Resource asymmetries: implications for the right to health

5.1. Economic accessibility

5.1.1. Access to technologies

The previous chapter argued that the DeepMind-NHS partnership risks exacerbating inequities in the NHS by making any resulting technological innovations more accessible to trusts with greater digital maturity and resource capacities, leaving those in greatest need of technological and health improvements least likely to benefit from them. It argued that fragmentation of the health system and the propagation of partnerships with commercial actors- both symptoms of neoliberal reform in the NHS- have contributed to this so-called 'innovation lottery' that determines access to technologies. My findings echo critics of the pharmaceutical industry- who condemn how powerful monopolies render drugs inaccessible through corporate price-gouging-[587] and give weight to critical data scholars' observation that novel forms of health inequity are emerging in the data economy.[588] Furthermore, much like the issue of access to medicines, these findings call into question the obligations of the state with respect to accessibility and equity under the rights to health and science.

[587] Clark & McGoey (n54); Ruckert & Labonté, (n54); Mazzucato et al (n208); McGoey et al (n245);Pratt & Loff (n54)
[588] Parry & Greenhoulgh (n68).

5.1.2. Economic accessibility under international human rights law

General Comment 14 describes four interrelated and essential elements of the right to health, often called the 'AAAQ' framework: the availability, accessibility, cultural acceptability, and quality of health facilities, goods and services.[589] Accessibility requires that States make health facilities, goods, and services accessible to all; this includes physical accessibility, economic accessibility, and information accessibility, as well as accessibility on the grounds of non-discrimination. Economic accessibility or affordability is therefore a key component of the right to health.

General Comment 14 further prescribes that economic accessibility should be based on the principle of equity. This demands that "payment for health-care services, as well as services related to the underlying determinants of health... whether privately or publicly provided, are affordable for all, including socially disadvantaged groups",[590] such that, "poorer households should not be disproportionately burdened with health expenses as compared to richer households".[591] The concept of equity in human rights law is thus closely related to status and power,[592] social justice,[593] and the principles of non-discrimination and equality.[594] Though they are related, there is a crucial distinction between equity and

[589] General Comment 14 (n46), para 12.
[590] Ibid, para 12(b).
[591] Ibid.
[592] Audrey R. Chapman 'The social determinants of health, health equity, and human rights' (2010) Health Hum. Rights 12(2) 17-30.
[593] Paula Braveman & Sofia Gruskin 'Defining equity in health' (2003) J Epidemiol Commun H 57 254–258.
[594] Paula Braveman 'Health Disparities and Health Equity: Concepts and Measurement' (2006) Annu Rev Public Health 27 167–94.

equality; equity is an inherently normative concept, as it implies some kind of judgement about whether the processes driving inequality are unjust or unfair,[595] whereas equality is "the metric by which health equity is assessed".[596]

States also have a duty to protect the right to health, which requires them to ensure that privatisation in the health sector does not constitute a threat to the availability, accessibility, acceptability and quality of health facilities, goods and services.[597]

Further to this, States have obligations with respect to the accessibility of health technologies under the right to benefit from scientific progress and its applications. As specified under General Comment 25, the applications of scientific progress refers to the material results of scientific research, including vaccinations, fertilizers and technological instruments.[598] As a result, the CESCR has stressed, the right to science is instrumental in realizing the right to health and states must "ensure that their legal or other regimes for the protection of the moral and material interests resulting from one's scientific, literary or artistic productions constitute no impediment to their ability to comply with their core obligations in relation to the right(s) to... health...".[599]

The CESCR has further emphasised the critical role of intellectual property in mediating the relationship between the rights to science and health, arguing that intellectual property "may, in some cases, pose significant obstacles for persons wishing to access the benefits of scientific progress, which may be crucial for the enjoyment of other economic, social and cultural rights, such as the right to

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[595] Braveman & Gruskin (n593).
[596] Paula Braveman 'Social conditions, health equity, and human rights' (2010) Health Hum Rights 12(2) 31-48.
[597] General Comment 14 (n46), para 35.
[598] CESCR General Comment 25 (n87), para 8.
[599] CESCR General Comment 25 (n87), para 35 (words omitted and brackets added for emphasis).

health".[600] Where patents grant patent holders exclusive rights to exploit the product or service they have invented, the Committee states, they can determine a price for these products and services which, if set high, may restrict access for low-income persons or developing countries.[601] This is problematic for the right to science, which obligates State parties to "ensure that everyone has equal access to the applications of science, particularly when they are instrumental for the enjoyment of other economic, social and cultural rights".[602]

5.1.3. Access to health technologies: implications for the right to health

In light of the UK government's obligation to make health goods and services- including new medical applications resulting from scientific research- accessible to all NHS patients on an equitable basis, the DeepMind-NHS partnership risks infringing upon the rights to health and science by generating inequities in access to technologies between NHS trusts and their patients. It highlights how the NHS' 'innovation lottery'[603] has serious implications for NHS patients' socioeconomic rights and casts doubt on the DeepMind-NHS trust-level, demand-driven partnership model as a means for the UK government to realise equitable access to health technologies and advance the rights to health and science. This finding exemplifies Chapman's

[600] CESCR General Comment 25 (n87), para 61.
[601] CESCR General Comment 25 (n87), para 61.
[602] CESCR General Comment 25 (n87), para 17.
[603] Thomas et al (n505).

argument that the fragmentation of health systems like the NHS complicates realisation of the right to health.[604]

Further to this, my political economic analysis suggests that DeepMind's role in the provision of data-driven technologies- in particular, the company's claims to exclusive intellectual property rights- may compromise the accessibility of these technologies by enabling corporate price-gouging that renders them unaffordable to some or all NHS trusts and their patients. As a result, the DeepMind-NHS partnership could also infringe upon the UK government's duty to protect the financial accessibility of health technologies under the right to health, supporting the view that "the commercialization of health care in some cases shapes and in others aggravates the inequitable distribution of health facilities, goods, and services".[605]

Together, these findings point to the risks that DeepMind's exclusive intellectual property rights pose to the accessibility and equitable provision of health technologies under the rights to health and science, reinforcing the instrumental role of the right to science in realising the right to health in the digital age. Much like the longstanding tension between corporate profit-making and the right to health in the access to medicines debate, in which pharmaceutical monopolies' patent rights over new drugs have enabled corporate price-gouging and restricted access to life-saving drugs for many of the world's most vulnerable people, the emerging issue of access to data-driven technologies in health raises similar questions around the appropriate relationship between the public and private sectors, the just allocation of responsibilities between them and the mechanisms necessary to facilitate this.[606] It

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[604] Audrey Chapman, 'The impact of reliance on private sector health services on the right to health' (2014) Health Hum Rights 16(1) 122-33.
[605] Audrey Chapman, 'Global Health, Human Rights, and the Challenge of Neoliberal Policies' (2016, Cambridge University Press), 105
[606] Lisa Forman & Jillian Clare Kohler, 'Chapter One: Introduction: Access to Medicines as a Human Right – What Does it Mean for Pharmaceutical Industry Responsibilities?', in Lisa Forman & Jillian

highlights how the IP system in its current form presents a persistent challenge to the realisation of the right to health, reinforcing calls for IP rights to be considered within a broader legal framework that includes international human rights law.[607]

Despite these similarities, my findings also highlight the novel challenges posed by access to data-driven technologies in health, particularly the issue of digital divides. They demonstrate how neoliberal reforms to fragment the NHS not only generated financial inequity between trusts but also differences in digital infrastructure and expertise that further exacerbate the inequitable provision of health goods and services across the system. My findings thus provide support for Sun et al's view that emerging technologies may exacerbate inequalities and widen digital divides, raising particular concerns around accessibility under the right to health, and highlight the need for greater consideration of the impact of AI projects on the broader health systems in which they are implemented.[608]

5.2. Resource availability

5.2.1. Data extractivism through DeepMind-NHS

The previous chapter revealed that the DeepMind-NHS partnership grants exclusive rights to developed IP- and with it entitlements to any scientific and commercial benefits of the collaboration- to Google Health. This finding exemplifies how technology companies like Google pursue an innovation strategy of 'data

Clare Kohler (eds.), 'Access to Medicines as a Human Right: Implications for Pharmaceutical Industry Responsibility' (2012, University of Toronto Press); Grover et al (n43); Lee & Hunt (n45).

[607] Abbe E.L. Brown, 'Intellectual Property, Human Rights and Competition' (2012, Edward Elgar), pg. 55.

[608] Williams (n98); Sun et al (n98).

rentiership' "designed to capture and extract value through ownership and control of data as an asset",[609] which renders them increasingly wealthy "de facto monopolies".[610] It further supports the view that corporations capitalise on collaborative public-private innovation processes to extract wealth through a system of socialized risk and privatized reward, enabling them to reap disproportionate rewards.[611] This finding calls into question the UK government's resource availability obligations under the ICESCR.

5.2.2. Resource availability in international human rights law

Article 2(1) of the ICESCR states that all signatories to the Covenant agree "to take steps, individually and through international assistance and co-operation, especially economic and technical, *to the maximum of its available resources*, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means...".[612] The duty to use maximum available resources (MAR) "means that a government must do all that it can to mobilize resources within the country in order to have funds available to progressively realise ESC rights".[613] This means governments have a legal obligation to use their resources both efficiently and effectively; that is, policies and programmes must be cost-effective, as well as delivering on their promise of improving human rights.[614] Where necessary, states also have a duty to provide

[609] Birch et al (n40) 3.
[610] Ibid.
[611] Mazzucato (n39); McGoey (n51).
[612] ICESCR (n101).
[613] Ann Blyberg & Helena Hofbauer 'Article 2 & Governments' Budgets' (2014) <www.internationalbudget.org/wp-content/uploads/Article-2-and-Governments-Budgets.pdf> accessed 10 August 2020.
[614] Ibid.

international assistance to countries that do not have the resources to meet their socio-economic rights responsibilities.[615]

The financial component of MAR- and particularly the close connection between MAR and budgetary analysis- has been the primary focus of much of the scholarship on available resources,[616] reflecting a tendency to view available resources in purely or predominantly financial terms.[617] However, available resources also include a range of non-financial resources, which have received less attention from human rights scholars. Robertson argues for a broader conception of resources, including financial, natural, human, technological and information resources.[618] However, no list can be truly definitive, the author argues, as "the ongoing process of economic and social evolution is constantly creating different resource needs";[619] his comment highlights the need for analysis of MAR to be responsive to economic and social development.

Skogly suggests that the current quantitative approach to resource availability- which focuses primarily on the availability of financial resources- may have excused states from implementing human rights to their maximum potential.[620] Instead, the author calls for a renewed focus on the qualitative dimensions of MAR; that is, a focus on the means of implementation of resources as opposed to the quantity of resources themselves. Adopting this approach, Skogly calls not only for a

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[615] UNHRC 'General Comment No. 3: The Nature of States Parties' Obligations (Art. 2, Para. 1, of the Covenant)' (1990) UN Doc E/1991/23.
[616] Diane Elson et al 'Public Finance, Maximum Available Resources And Human Rights' in Aoife Nolan, Rory O'Connell & Colin Harvey (eds) *Human Rights and Public Finance: Budgets and the Promotion of Economic and Social Rights* (Hart Publishing, 2013) 13-40; Blyberg & Hofbauer (n176).
[617] Elson et al (n616).
[618] Robert E. Robertson 'Measuring State Compliance with the Obligation to Devote the Maximum Available Resources to Realizing Economic, Social and Cultural Rights' (1994) Hum Rts Q 16 693-714.
[619] Ibid 695.
[620] Sigrun Skogly 'The Requirement of Using the 'Maximum of Available Resources' for Human Rights Realisation: A Question of Quality as Well as Quantity?' (2012) Hum Rts L Rev 12(3) 393-420.

more expansive understanding of resources- as encompassing natural, human, cultural, scientific, technological, financial and legislative means- but also for the creative and effective use of existing resources as a more efficient and sustainable means of advancing socio-economic rights.

Human rights scholars have drawn attention to a potential role for the private sector in making resources 'available' for the realisation of socio-economic rights. Robertson argues that the state's obligations extend beyond those resources over which it has direct control; thus, "in addition to allowing and encouraging voluntary use of private resources, states must also consider strategies for their appropriation".[621] Along similar lines, Skogly suggests that states can better implement socio-economic rights by including financial contributions from private sources.[622] Balakrishnan et al are more specific, proposing that private contributions to the fulfilment of socio-economic rights might be 'leveraged' through co-responsibility or public-private partnership.[623]

5.2.3. Data extractivism through DeepMind-NHS: implications for resource availability

The data extractivist model underlying DeepMind-NHS- in which Google are able to capture all the scientific and commercial value of publicly-funded patient data- raises questions about the nature and value of health data and its relationship to Article 2(1) of the ICESCR.

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[621] Robertson (n618) 699.
[622] Skogly (n620) 410.
[623] Balakrishnan et al *Maximum Available Resources & Human Rights* (Rutgers: The State University of New Jersey, 2011).

Socioeconomic rights scholars have argued that Article 2(1) should be interpreted expansively to include natural, human, cultural, scientific, information, technological, financial and legislative resources.[624] Under the DeepMind-NHS partnership, the patient data shared with DeepMind is a source of information, scientific advancement, technological innovation and financial gain, reflecting the complexity of valuing health data in the context of an emerging health data economy. Thus, under an expansive interpretation of available resources, patient data may be categorised as an information, scientific, technological or financial resource, placing concomitant obligations on the UK government with respect to Article 2(1) of the ICESCR.

Conceptualising the patient data shared under DeepMind-NHS as an available resource that the UK government should use to progressively realise socioeconomic rights draws attention to the problematic nature of the data extractivist model underlying the partnership. Socioeconomic rights scholars have argued that PPPs may be used by states as a means of leveraging private sector contributions to advance socioeconomic rights.[625] However, my analysis of the political economy of DeepMind-NHS suggests that, to the contrary, the collaboration facilitates a form of data extractivism that enables the corporate capture of any scientific and commercial benefits. Thus, instead of leveraging its data resources through PPP, the UK government instead risks failing to realise its resource availability obligations under the ICESCR by squandering the value of health data in ways that infringe upon the realisation of socioeconomic rights.

[624] Skogly (n620); Robertson (n618)
[625] Balakrishnan et al (n623)

This calls into question the effectiveness of data-driven research partnerships like DeepMind-NHS as a means of realising the value of NHS data resources and advancing socioeconomic rights, highlighting the need for the UK government to consider how alternative arrangements may prevent socioeconomic rights infringements by commercial actors and enable the state to fulfil its resource availability obligations under the ICESCR. That health data is valuable in a multitude of ways suggests its potential utility as a resource to advance socioeconomic rights is great. This is particularly true of NHS data, whose universality, longitudinal nature, and use of single patient identifiers make it especially attractive to technological innovators.[626] In light of the NHS's budgetary and resource constraints, patient data resources may thus have an important role to play in the progressive realisation of socioeconomic rights in the UK, reinforcing Skogly's calls for states to use their existing resources creatively and effectively to meet their socioeconomic rights obligations.[627]

Conceptualising health data as an available resource to realise the right to health does, however, raise some ethical and practical issues. Firstly, the extent to which we can describe data as 'available' is dependent on a number of practical factors like data quality. Harry Evans, policy researcher at The King's Fund, drew attention to the issue of data quality in our interview:

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[626] Recent attempts to value the NHS dataset estimated it could be worth almost £10 billion in total. See Owen Hughes 'NHS Data Worth £9.6Bn Per Year, Says Ernst & Young' (*Digital Health*, 24 July 2019) <www.digitalhealth.net/2019/07/nhs-data-worth-9-6bn-per-year-says-ernst-young/> accessed 10 August 2020.

[627] Skogly (n162); For a recent review of NHS financial sustainability, see National Audit Office 'NHS financial sustainability' (18 January 2019) HC 1867 Session 2017-2019 <www.nao.org.uk/wp-content/uploads/2019/01/NHS-financial-sustainability_.pdf> accessed 1 September 2020.

"Data quality is really important at the moment and is not being talked about nearly enough... We talk about this vast treasure trove of patient data but it's not really in a mineable form at the moment. We need to put quite a lot of effort into getting that dataset into a position where you can use it for some of these kinds of analyses. I've heard of companies having to hire hospital consultants to do a whole load of labelling and coding of data just to get the dataset to a state where they can start using it for their analysis."

His comment underscores the critical importance of data quality in determining the potential of health data as a resource to advance the right to health, reinforcing Skogly's calls for greater focus on the quality of available resources.[628]

Furthermore, risks of health data misuse may lead to violations of the right to privacy or other civil and political rights, particularly where commercial actors are involved.[629] In light of the privacy scandal surrounding DeepMind-NHS and the controversial data practices of companies like Google, any determination of the availability of data resources as a means of realising the right to health must urgently consider potential risks and balance different human rights considerations accordingly.

My findings point to the limitations of macroeconomic analysis in assessing resource availability under the ICESCR in the context of the emerging health data economy, in which the value of patient data is both increasing and becoming ever more complex to ascertain. It thus provides weight to the case for a more expansive interpretation of available resources, highlighting the need for socioeconomic rights

[628] Skogly (n620).
[629] OHCHR (n368); Ursin (n383).

scholars to remain responsive to technological change and to interpret socioeconomic rights frameworks accordingly.[630]

5.3. The resource trade-off and the right to health paradox

The proceeding chapter argued that DeepMind-NHS is expected to deliver mutual benefits, including public benefits such as improvements in the efficiency and quality of NHS services, the development of disruptive innovations and reputational gains for NHS partners. These claims are significant with respect to the right to health as they suggest the partnership has the potential to improve the availability, accessibility and quality of health goods and services, which are key components of the AAAQ framework.[631] This points to the possibility that data-driven research partnerships like DeepMind-NHS could advance the right to health, giving weight to the views of right to health scholars who highlight the potential of digital technologies to improve healthcare and support the realisation of the right to health.[632]

Despite this, my analysis has revealed how the partnership in fact gives rise to resource asymmetries between Google and the NHS, allocating the scientific and commercial benefits of the collaboration- and the ability to control access to resulting health benefits- to Google, with detrimental impacts for accessibility, equity and resource availability under the right to health. Underlying this resource trade-off is thus a right to health paradox; that the promise of advancing the right to health

[630] Robertson (n618); Skogly (n620).
[631] General Comment 14 (n46).
[632] Williams (n98); Sun et al (n98)

through the development of new digital technologies with commercial actors may conversely prove detrimental to its realisation. This supports Davis' contention that digital health technologies may be a 'trojan horse' for the private sector, enabling commercial actors to covertly benefit significantly from PPPs at the expense of the state's ability to discharge its right to health obligations.[633]

This finding highlights how neoliberal policies- including the expansion of IP systems, the fragmentation of health systems, and the introduction of PPP governance models- generate a political economic reality that constrains the realisation of the right to health. Though such policies do not amount to direct or egregious human rights violations, they nonetheless significantly shape the capacities of states and non-state actors to discharge their socio-economic rights obligations. Partnerships like DeepMind-NHS thus illustrate the risks that economic violations- that is, "those acts, by states or businesses, that breach relevant doctrines through economic practices that adversely affect access to rights"-[634] pose to socioeconomic rights like the right to health. This exemplifies Birchall's view that corporate actors can exert structural power over human rights through materialities "as a mediating site through which uneven power relationships are exploited",[635] highlighting the importance of political economy in shaping the material conditions underlying the realisation of the right to health and reinforcing calls for greater attention to political economy in human rights analysis.[636]

Further to this, the right to health resource paradox underlying DeepMind-NHS reveals how the distributive requirements of the right to health have evolved in

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[633] Davis (n98).
[634] Birchall (n179) 9.
[635] David Birchall, 'Corporate Power over Human Rights: An Analytical Framework' (2020) Business and Human Rights Journal 6(1), 51.
[636] Ibid; Kapczynski (n180).

the data economy. It reinforces the significance of digital divides in realising the right to health benefits of digital technologies and also highlights the need for states to acknowledge the importance of health data as a public asset, utilising it to advance the right to health and protecting it from commercial exploitation accordingly. The shortcomings of DeepMind-NHS in addressing these challenges for the right to health in the digital age highlights the need for the UK government to consider alternative models for data-driven innovation, demonstrating how international human rights law has a significant role to play in critical data scholarship and its efforts to shape a more equitable data economy.

5.4. Conclusion

This chapter analysed asymmetries in the distribution of resources in DeepMind-NHS through the lens of the right to health, focusing on the state obligations to make health technologies financially accessible on an equitable basis and to use maximum available resources to progressively realise the right to health. It argued that Google's exclusive intellectual property rights under the partnership pose a risk to the accessibility and equitable provision of health technologies under the rights to health and science, raising questions about the relationship between and responsibilities of public and private sectors in facilitating access to technologies and highlighting the persistent challenge that IP systems pose to the right to health. It further argued that the data extractivist model underlying the partnership highlights the need for health data to be conceived of as a resource to progressively realise the right to health and called into question the effectiveness of DeepMind-NHS in leveraging available data resources to this effect. The final section argued that the

resource trade-off underlying DeepMind-NHS reveals a right to health paradox, such that the promise of collaborating with commercial actors to advance the right to health through data-driven innovation may conversely prove detrimental to its realisation, reinforcing the close connection between structural power in the political economy and the right to health and highlighting the evolving nature of the distributive obligations contained in the right to health in the digital age.

Chapter 6: Knowledge asymmetries: implications for the right to health

6.1. Transparency

6.1.1. Public sector secrecy

In Chapter Five, my analysis of the political economy of DeepMind-NHS drew attention to the lack of transparency surrounding the collaboration. The partnership with the Royal Free Hospital NHS Foundation Trust was first publicly announced in November 2016, over a year after the data transfer took place and six months after Hodson's revelatory New Scientist article. In addition, both DeepMind and the NHS had far greater ambitions for the collaboration than the Streams project alone, which were not clearly made known to the public. Further to this, details of the collaboration were only revealed through the investigatory work of journalist Hodson, who relied upon the use of FOI requests that were often complex to interpret. The use of commercial confidentiality laws also acted as a barrier to disclosure of important commercial details of the collaboration. This opacity was further exacerbated by the systemic lack of public sector transparency surrounding commercial deals in the NHS.

6.1.2. Transparency and the right to health

In the context of the right to health, accountability refers to "the process which requires government to show, explain and justify how it has discharged its obligations regarding the right to the highest attainable standard of health".[637] Though definitions of accountability differ among right to health scholars, I adopt Williams and Hunt's tripartite conceptualisation of accountability as monitoring, review, and remedial action.[638]

Transparency is a critical component of state accountability for the right to health. States are required to monitor all aspect of policy development and implementation on a continuous basis;[639] this process relies on reliable and transparent data, which provides rights-holders with the information necessary to hold the state accountable for violations of the right to health.[640] This data is then analysed and used to review whether a state's human rights commitments have been met; [641] this process should be independent, highlight successes and shortcomings, provide recommendations for improvement, and extend to non-state actors.[642] Finally, remedial action ensures that victims of violations of the right to health "should have access to effective judicial or other appropriate remedies at both national and international levels".[643]

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[637] Potts (n109).
[638] Williams & Hunt (n157).
[639] Qiu & MacNaughton (n158).
[640] Williams & Hunt (n157); Qiu & MacNaughton (n158).
[641] Williams & Hunt (n157).
[642] WHO, 'Keeping Promises, Measuring Results' (Commission on Information and Accountability for Women's and Children's Health, Geneva, 2011) <www.who.int/topics/millennium_development_goals/accountability_commission/Commission_Report_advance_copy.pdf?ua=1> accessed 10 August 2020.
[643] General Comment 14 (n46).

6.1.3. Public sector secrecy: implications for transparency and the right to health

In light of the UK government's right to health accountability obligations and its duty to protect the right to health from corporate transgressions, the lack of transparency surrounding the DeepMind-Royal Free deal and the subsequent partnerships between the company and the NHS are problematic. Effective monitoring and review of the state's right to health obligations relies on access to reliable and transparent data. The difficulty of obtaining access to and interpreting reliable information about the details of DeepMind-NHS thus restricts the ability of rights-holders to hold the state accountable for its right to health obligations in the partnership and prevents the state from effectively monitoring and reviewing the progress of the partnership in advancing the right to health.

The impact of this transparency deficit on monitoring and review draws attention to shortcomings in the UK government's accountability for the right to health under data-driven research partnerships like DeepMind-NHS. It supports the views of right to health scholars who argue that opacity surrounding scientific innovation is detrimental for right to health accountability and emphasise the need for disclosure surrounding PPPs in the provision of health goods and services.[644] It further highlights how neoliberal policy- including strict commercial confidentiality protections and the rollback of state oversight and regulation of commercial actors- can act as a barrier to socioeconomic rights accountability.

[644] Trudo Lemmens & Candice Telfer 'Access to information and the right to health' (2012) AM JL & Med 38; UNGA 'The right to health: Note by the Secretary-General' (11 August 2008) UN Doc A/63/263, 21.

6.2. Corporate responsibility to respect and state duty to protect the right to health

6.2.1. DeepMind Health's engagement with CSR and ethics

My analysis of the political economy of DeepMind-NHS highlighted how the company's lack of profitability and blue-sky mission, philanthropic leadership, establishment of an Independent Review Panel, and engagement with patient and public participation and AI ethics generated an image of the company as a benevolent research organisation operating in the public interest, exemplifying the rise of health data entrepreneurism in the data economy and revealing the potential for PPPs to advance good governance values.[645]

Despite this, the DeepMind-NHS partnership also generated knowledge asymmetries; it lacked adequate public sector transparency and covertly enabled Google to expand its reach into healthcare, despite the company's lack of transparency and accountability. These knowledge asymmetries cast doubt on DeepMind Health's public image as a socially-responsible research organisation, shedding light of knowledge trade-off underlying DeepMind-NHS; that collaboration with a seemingly publicly-accountable research organisation comes at the expense of the covert expansion of the power and influence of the monopolistic technology giants. They point to the 'toothlessness' of voluntary corporate goodwill in the face of

[645] Prainsack (n73); Brinkerhoff & Brinkerhoff (n39); Hood et al (n55); Reich (n59).

shareholder interests, highlighting the need to remain critical of such initiatives and to ensure robust accountability mechanisms.[646]

6.2.2. Corporate responsibility to respect and State obligation to protect the right to health under human rights law

Under the Guiding Principles, the corporate responsibility to respect means businesses "should avoid infringing on the human rights of others and should address adverse human rights impacts with which they are involved".[647] This requires that commercial actors avoid contributing to negative human rights impacts and address them when they occur.[648] The Principles stress that these responsibilities apply to all business enterprises "regardless of their size, sector, operational context, ownership and structure";[649] however, they recognise that a company's ability to address adverse human rights impacts might vary according to these factors.

The Principles state that the responsibility to respect must be operationalised through the appropriate policies and processes, including a policy commitment to respect human rights, a human rights due diligence process, and processes to enable the remediation of human rights violations.[650] The statement of policy should be endorsed by senior management of the corporation, be informed by internal and/or external expertise, stipulate human rights expectations of key stakeholders,

[646] Cath (n73); Vaidhyanathan (n73); Mittelstadt (n324).
[647] The Guiding Principles (n137) para 11.
[648] Ibid para 13.
[649] Ibid para 14.
[650] Ibid para 15.

be publicly available, and be embedded in the corporation through operational policies and procedures.[651]

Corporate human rights due diligence processes should cover all adverse human rights implications the corporation is directly or indirectly linked to, vary in relation to features of the corporation- such as size, risk of human rights impacts, and the nature of context of its operations- and be ongoing, "recognizing that the human rights risks may change over time as the business enterprise's operations and operating context evolve".[652] The process of identifying and assessing human rights risks should draw on internal and/or external human rights expertise and involve meaningful engagement with relevant stakeholders and affected groups.[653] This process may be incorporated into other assessment processes- though must include all human rights- and should be undertaken periodically, when instigating a new activity, relationship, operational decision, and where the operating environment changes.[654]

Findings from human rights impact assessments (HRIA) must be integrated into business practices and their effectiveness tracked,[655] and commercial actors should communicate their findings externally.[656] All communications should be of an appropriate form and frequency and available to their intended audience, provide information sufficient to assess the company's response to human rights risks, and not pose risks to stakeholders or to 'legitimate requirements' of corporate

[651] Ibid para 16.
[652] Ibid para 17(c).
[653] Ibid para 18.
[654] Ibid para 18.
[655] Ibid paras 19 & 20.
[656] Ibid para 21.

confidentiality.[657] Commercial actors are also obligated to contribute to or provide remediation where rights violations have occurred.[658]

Human rights due diligence is also an important component of the state duty to protect the right to health from infringements by third parties. The Guiding Principles require states to provide guidance on how to respect human rights, which should indicate expected outcomes, facilitate sharing of best practices and advise on methods like due diligence procedures. Furthermore, States should encourage businesses to communicate how they address human rights issues; this can range from "informal engagement with affected stakeholders to formal public reporting"[659] and should account for risks to the safety of individuals, commercial confidentiality and the size and structure of the company.[660]

6.2.3. DeepMind Health's engagement with CSR and ethics: implications for corporate and state right to health obligations

In light of its responsibility to respect human rights under the UN Guiding Principles, DeepMind Health's voluntary accountability and participatory mechanisms and engagement with corporate social responsibility falls short of its right to health responsibilities. The Guiding Principles require business enterprises to provide a human rights policy statement;[661] DeepMind made no such commitment to respect human rights, despite its purported commitment to using AI ethically and for societal good. Human rights are mentioned briefly in the Partnership on AI's tenets, which

[657] Ibid para 21.
[658] Ibid para 22.
[659] Ibid.
[660] Ibid.
[661] Ibid para 16.

states that all signatories will oppose the "development and use of AI technologies that would violate international conventions or human rights and promoting safeguards and technologies that do no harm".[662] However, this selective commitment falls far short of the comprehensive policy statement on human rights that the Guiding Principles recommends, which would demonstrate the company's commitment to all human rights, including the right to health. It thus supports Soh and Connelly's view that technology corporations selectively utilise and reinterpret human rights to be compatible with their business models.[663]

By contrast, Google has made an explicit policy commitment to human rights, in which it claims that, "in everything we do, we are guided by internationally recognised human rights standards...", including the UDHR and the Guiding Principles.[664] Though this explicit commitment is important, the company provides no further clarity on how it expects to operationalise these rights throughout the organisation, including Google Health. Google has also committed to respect civil and political rights through the Global Network Initiative-[665] a multi-stakeholder platform to promote the rights to privacy and freedom of expression in the technology sector- and its own set of AI principles.[666] The AAAS' Theresa Harris drew attention to this point in our interview:

"Google is a member of the Global Network Initiative, which has all these statements about the right to privacy, the right to freedom of expression... but they haven't necessarily looked at some of the other human rights."

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[662] 'Tenets' <www.partnershiponai.org/tenets/> accessed 11 August 2020.
[663] Soh & Connolly (n182) 180.
[664] 'Human Rights' <https://about.google/human-rights/> accessed 11 August 2020.
[665] 'About GNI' <https://globalnetworkinitiative.org/about-gni/> accessed 11 August 2020.
[666] Sundar Pinchai 'AI at Google: our principles' (*The Keyword (Google)*, 7 June 2018) <www.blog.google/topics/ai/ai-principles/> accessed 11 August 2020.

Her comment highlights how- despite such initiatives being a welcome development- their sole focus on civil and political rights means that the impacts of new technologies for other human rights, including the right to health, are neglected. This lends weight to Soh and Connelly's argument that the Global Network Initiative is focused predominantly on government surveillance and thus fails to address the negative consequences of corporate profit-making.[667] This predominant focus on civil and political over socioeconomic rights supports the view that risks tend to be prioritised over 'soft' impacts in discussions around technology policy.[668]

Further to this, though the company did conduct Privacy Impact Assessments (PIAs) when entering into partnership with the NHS, their restrictive focus on data protection and patient privacy does not amount to the wide-ranging, ongoing human rights due diligence obligations explicated in the Guiding Principles.[669] In addition, since DeepMind's contracts with the NHS have been transferred to Google Health, no evidence has emerged of Google engaging in any human rights due diligence processes. Given the controversy surrounding DeepMind's dealings with the NHS and the fact that companies can inherit human rights risks through mergers and acquisitions,[670] this lack of due diligence appears at odds with Google's policy commitment to human rights. In the absence of a HRIA, no information about the human rights risks of the partnership has been made publicly available by DeepMind or Google; this acts as a substantial barrier to the company's ability to mitigate any

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[667] Soh & Connolly (n182) 174.
[668] Swierstra & Molder (n43).
[669] 'Privacy Impact Assessment Google DeepMind Streams Royal Free London NHS Foundation Trust' <http://s3-eu-west-1.amazonaws.com/files.royalfree.nhs.uk/Privacy_Impact_Assessment___Streams___Royal_Free_Hospital.pdf> accessed 11 August 2020; The PIA with the Royal Free was written after the data transfer had already occurred.
[670] The Guiding Principles (n137) para 18.

human rights risks or integrate these findings into company functions and processes, as is recommended by the Guiding Principles.

Assessing DeepMind Health's voluntary accountability mechanisms and corporate social responsibility through the framework of the Guiding Principles reveals that- despite its public image as a socially-responsible research organisation- the company failed to respect its right to health responsibilities in the DeepMind-NHS collaboration. This absence of human rights due diligence further calls into question the UK government's duty to protect the right to health from infringements by commercial actors.

These findings highlight how DeepMind Health's engagement in 'ethical' or socially responsible behaviour does not mean the company has effectively discharged its right to health responsibilities under the Guiding Principles. They draw attention to the important distinction between the business and human rights framework- which benefits from a strong legal foundation and a prescriptive procedural framework-[671] and the notion of corporate social responsibility, the foundations, nature and scope of which are less clearly defined.

Voluntary corporate social responsibility and ethical initiatives in the area of emerging technologies abound; though such efforts are welcome, socially responsible behaviour does not absolve technology companies like DeepMind of their human rights responsibilities under international human rights law. Furthermore, corporate engagement with CSR may risk inadvertently obscuring non-compliance with the Guiding Principles where the distinction between socially-responsible behaviour and soft law human rights responsibilities is not acknowledged and reinforced by states and commercial actors. My findings thus support the view that

[671] Mittelstadt (n324).

technology companies should prioritise compliance with their legal responsibilities under the Guiding Principles rather than viewing them as an adjunct to or component of their broader CSR agenda.[672]

Despite this, DeepMind and Google's neglect of their responsibility to respect human rights also exemplifies the limitations of the Guiding Principles' voluntarism, which enables commercial actors to disregard and/or violate human rights with impunity. This highlights how- despite their differing ideological, legal and procedural bases- corporate social responsibility and the current business and human rights framework are both similarly limited in their capacity to hold companies liable for their actions. The following section explores this and other limitations of the Guiding Principles as they apply to DeepMind-NHS in greater depth.

6.3. The limitations of corporate right to health responsibilities

6.3.1. The 'Googlization' of health

My analysis of the political economy of DeepMind-NHS revealed how the partnership has covertly expanded the power and influence of Google. Critics had been cautious of DeepMind's relationship to Google from the offset; however, for some time, DeepMind remained secretive about its business model and emphasised its separation from sister company Google. In November 2018, this illusion was shattered when DeepMind Health was subsumed under Google Health, exemplifying

[672] Sun et al (n98) 24.

how the technology giants utilise a 'one-way mirror' and a culture of strategic mergers and acquisitions to expand into healthcare markets. Google's takeover of DeepMind-NHS is especially problematic when we consider the company's disregard for privacy and anti-trust law and its increasingly prominent role in policymaking and research, evidence of its lack of accountability and the limitations of efforts to effectively regulate Big Tech.

6.3.2. Limitations of corporate responsibility for the right to health under the Guiding Principles

6.3.2.1. Non-binding

The Guiding Principles grew out of a recognition that multinational corporations were becoming ever more powerful and were increasingly implicated in human rights abuses, pointing to the need for greater corporate accountability. However, some human rights scholars argue they have failed to achieve this aim.[673]

Muchlinksi characterizes the Guiding Principles as a form of 'institutionalized voluntarism' that represents a compromise between greater procedural commitments to mitigate human rights risks in commercial activities and full legal liability under international law.[674] As such, despite creating the necessary conditions to improve

[673] Deva (n46); Wettstein (n46).
[674] Peter Muchlinski 'The Impact of the UN Guiding Principles on Business Attitudes to Observing Human Rights' (2021) Business and Human Rights Journal 1-15 https://doi.org/10.1017/bhj.2021.148.

corporate adherence to human rights, the author argues that Guiding Principles remain rooted in corporate voluntarism.[675]

Wettstein is sceptical of the Guiding Principles' voluntarism, highlighting how the use of weak terminology indicates different levels of expected commitment between corporation and state.[676] The Guiding Principles, he argues, thus "fall prey to the very problem they were supposed to fix, that is, the problem of growing governance gaps between companies' increasing sphere of activity and governments' decreasing ability or willingness to regulate them".[677]

Deva similarly condemns the use of weak terminology in the Guiding Principles, which has 'diluted' the responsibilities of business and undermined their normative value.[678] Furthermore, the instrument's focus on consensus-building, the author argues, afforded companies significant influence in the drafting process, legitimising their role in international law-making while rendering their human rights obligations under international law 'almost non-existent'.[679] This highlights how the Guiding Principles themselves are the product of what Birchall terms 'corporate power over knowledge'; that is, "the power that a corporation has to shape knowledge of human rights and the wider epistemic framework in which human rights exist".[680]

Bilchitz highlights that giving effect to voluntary, soft law instruments like the Guiding Principles relies on corporate goodwill and requires businesses to navigate the tension between their long-term social impact and short-term objective to

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[675] Ibid 9.
[676] Florian Wettstein, 'Normativity, Ethics, and the UN Guiding Principles on Business and Human Rights: A Critical Assessment' (2015) J Hum Rights 14(2) 162-182
[677] Ibid 166.
[678] Deva (n46) 79.
[679] Deva (n46); Wettstein (n676).
[680] Birchall (n635) 52.

maximise profit. In practice, he argues, there is wide recognition that this approach is flawed.[681]

The limitations of the Guiding Principles' voluntarism have led to mounting calls for stronger, legally-binding human rights regulation for corporations.[682] These have culminated in the proposition to develop a legally-binding UN Treaty on business and human rights, with an explicit focus on corporate accountability. This Treaty, proponents have argued, could move beyond the Guiding Principles' voluntarism to provide recognition, articulation and clarification of the legally-binding obligations of businesses under international human rights law.[683]

In June 2014, the UN Human Rights Council established an Intergovernmental Working Group (IGW) to "to elaborate an international legally binding instrument to regulate, in international human rights law, the activities of transnational corporations and other business enterprises".[684] In 2018, the IGW issued a preliminary draft of the Treaty- the 'Zero Draft'[685]- described as a 'key milestone' in the Treaty movement.[686]

The Zero Draft's focus was exclusively on transnational business operations and all corporate obligations were to be imposed indirectly through binding state duties. It enshrined state obligations with regards to the rights of victims of

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[681] Bilchitz, 'The Necessity for a Business and Human Rights Treaty' (2016) Business & Human Rights Journal 1(2): 203-227.
[682] Wettstein (n676); Deva (n46).
[683] Bilchitz (n681).
[684] UNHRC Res 26/9 (2014) UN Doc A/HRC/RES/26/9, para 1.
[685] UN OHCHR 'Legally Binding Instrument to Regulate, In International Human Rights Law, The Activities of Transnational Corporations and Other Business Enterprises' Zero Draft (16 July 2018) <www.ohchr.org/documents/hrbodies/hrcouncil/wgtranscorp/session3/draftlbi.pdf> accessed 10 August 2020 (Zero Draft).
[686] Phil Bloomer & Maysa Zorob 'Another Step on the Road? What does the "Zero Draft" Treaty mean for the Business and Human Rights movement?' (*Business and Human Rights Resource Centre Blog*, 14 August 2018) <www.business-humanrights.org/en/another-step-on-the-road-what-does-the-"zero-draft"-treaty-mean-for-the-business-and-human-rights-movement#> accessed 10 August 2020.

transnational corporate human rights abuses, legal liability, due diligence and mutual legal assistance, and proposed the creation of a committee of experts to monitor and promote implementation of the treaty.[687] The Zero Draft was praised for its strong emphasis on comprehensive, mandatory corporate human rights due diligence.[688] However, following a period of consultation and amendment, a revised draft was released in July 2019;[689] this expands the scope of the Treaty to include "all business activities, including but not limited to those of a transnational character".[690]

However, the revised treaty in its current state falls short of recognising direct corporate human rights obligations. In light of critiques of the Guiding Principles' inability to hold businesses accountable, the revised treaty thus reinforces the predominant state-centric paradigm of international human rights law and with it the notion that corporate human rights responsibilities are distinct from state obligations in their voluntariness and normative basis. This suggests the Treaty may be limited in its ability to address the fundamental problem of "growing governance gaps between companies' increasing sphere of activity and governments' decreasing ability or willingness to regulate them".[691]

By contrast, some scholars remain unconvinced that direct, legally-binding obligations are the solution to the corporate accountability gap. Van Ho suggests that the lack of enforcement of existing obligations is responsible for this deficit, arguing for an expansion of the jurisdiction of states as opposed to reformation of human

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[687] Zero Draft (n685) art 8, 9, 10 & 14.
[688] Bloomer & Zorob (n686).
[689] UN OHCHR 'Legally Binding Instrument to Regulate, In International Human Rights Law, The Activities of Transnational Corporations and Other Business Enterprises' OEIGWG Chairmanship Revised Draft (16 July 2019) <www.ohchr.org/Documents/HRBodies/HRCouncil/WGTransCorp/OEIGWG_RevisedDraft_LBI.pdf> accessed 10 August 2020 (Revised Draft).
[690] Ibid art 3.
[691] Wettstein (n676) 166.

rights instruments themselves.[692] The author contends that state-centrism offers the necessary tools to enforce greater corporate accountability- as well as greater authority and clarity than direct corporate obligations- and that the Treaty should not stray from this approach. Similarly, De Schutter supports the idea of a 'hybrid' model that clarifies the state duty to protect- including extraterritoriality- and imposes duties of mutual legal assistance on states but nonetheless adheres to the existing state-centric paradigm.[693]

The divergent views of BHR scholars on the question of binding corporate human rights obligations exemplify how the community remains divided on the best means to strengthen corporate human rights compliance.

6.3.2.2. Human rights minimalism

Critics of the Guiding Principles have also argued that the restrictive scope of corporate human rights responsibilities under this instrument provides inadequate protection for economic, social and cultural rights, leading to growing calls for a more extensive conception of corporate human rights responsibilities that obligate business to positively contribute towards the realisation of human rights.[694]

Aguirre highlights that the Principles' restrictive obligations have "little or no relevance within a global system dominated by economic factors and appeals to the bottom line of profit maximisation and economic growth in order to facilitate change

[692] Tara Van Ho ''Band-Aids Don't Fix Bullet Holes': In Defence of a Traditional State-Centric Approach' in Jernej Letnar Černič & Nicolas Carrillo-Santarelli (eds) 'The Future of Business and Human Rights: Theoretical and Practical Considerations for a UN Treaty' 1st ed (Intersentia, 2018) 111-138.
[693] Olivier De Schutter, 'Towards a New Treaty on Business and Human Rights' (2015) Business and Human Rights Journal 1(1): 41-67.
[694] Deva & Bilchitz (n116); Wettstein (n46); Wettstein (n676).

regarding the realisation of ESCR".[695] The author argues that corporations are uniquely placed to promote human rights by "increasing employment, increasing available capital, technology, knowledge, improved management and positive contributions to labour relations and administration".[696] Similarly, Wettstein suggests that recognition of corporations as political actors implies that "an adequate account of responsibility that matches this reality must extend far beyond merely doing no harm".[697] Birchall also draws attention to the fact that the Guiding Principles are rarely applied to economic violations in practice, with a focus on egregious and overt human rights violations.[698] Despite this, Ruggie's 'human rights minimalism' continues to predominate efforts to strengthen corporate human rights obligations under international law, including the proposed Treaty.[699]

The Guiding Principles have also been criticised for limiting the scope of corporate responsibility by requiring businesses only to respect human rights and not to protect or fulfil them. This restriction, critics argue, amounts to the responsibility to avoid violating human rights or to 'do no harm';[700] in other words, it imposes only negative responsibilities on commercial actors. For these critics, the Principles' restrictive scope or 'human rights minimalism' thus undermines the collective and collaborative problem solving that is necessary for the realisation of human rights.[701] This restrictive scope is also particularly problematic for socio-economic rights like

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[695] Daniel Aguirre 'Multinational Corporations and the Realisation of Economic, Social and Cultural Rights' (2004) Cal W Int'l LJ 35 53-82, 54.
[696] Ibid 64.
[697] Wettstein (n46) 172.
[698] Birchall (n179) 12.
[699] Zero Draft (n685); Revised Draft (n689).
[700] Deva & Bilchitz (n116); Wettstein (n46).
[701] Wettstein (n676); Wettstein (n46); David Bilchitz 'A chasm between 'is' and 'ought'? A critique of the normative foundations of the SRSG's Framework and the Guiding Principles' in Surya Deva & David Bilchitz (eds) *Human rights obligations of business: beyond the corporate responsibility to protect* (Cambridge University Press, 2013).

the right to health, as recognition of violations of the obligation to respect human rights relies on clear identification of violation, violator, and potential remedy, which "is best achieved when misconduct can be portrayed as arbitrary or discriminatory rather than a matter of purely distributive justice".[702] Economic violations are often the consequence of structural processes which implicate multiple actors and different forms of corporate power, meaning they are not easily remedied.[703] Limiting corporate responsibility to the obligation to respect thus provides limited accountability for violations of socio-economic rights like the right to health. Furthermore, the separation of duties in the context of economic, social and cultural rights is itself fuzzy,[704] which raises questions about the practical application of corporate responsibilities and the legitimacy of the rigid separation of duties in this context.[705]

6.3.3. The 'Googlization' of health: implications for the limitations of corporate right to health responsibilities

In light of critiques of the limitations of the UN Guiding Principles as a soft law instrument, Google's lack of accountability under DeepMind-NHS raises some fundamental challenges for the existing, state-centric system.

The company's growing influence over policymaking and regulatory efforts in the field of health data governance and data-driven technologies in the UK suggests

[702] Kenneth Roth 'Defending Economic, Social and Cultural Rights: Practical Issues Faced by an International Human Rights Organization' (2004) Hum Rts Q 26(1) 63-73, 63.
[703] Justine Nolan & Luke Taylor 'Corporate Responsibility for Economic, Social and Cultural Rights: Rights in Search of a Remedy?' (2009) J Bus Ethics 87(2) 433-451; Wettstein (n676); Birchall (n179).
[704] Wettstein (n46)
[705] Ibid.

the government's duty to protect the right to health under the Guiding Principles- which requires the state to use effective policies, legislation and regulation- may be compromised by corporate bias. This gives weight to Birchall's claims that the Guiding Principles are limited in their capacity to address corporate power over institutions, which nonetheless impacts the realisation of socioeconomic rights.[706]

The limited capacity of the UK government to protect the right to health in DeepMind-NHS is further challenged by Google Health's strategic merger with DeepMind Health. The merger exemplifies both the complex organisational structure and supranational commercial operations of the Alphabet conglomerate, which complicates the clear assignment of human rights obligations under the existing state-centric framework.[707] This raises further questions about the adequacy of the Guiding Principles' state-centrism in addressing the human rights risks posed by technology companies like Google.

Further to this, Google's disregard for privacy norms and anti-trust and tax law suggest that the company's soft law responsibilities under the Guiding Principles are unlikely to be respected and may prove ineffectual in altering the company's controversial behaviours. The proceeding section of this chapter provides evidence to support this, arguing that Google has not made serious efforts to implement the Guiding Principles in the DeepMind-NHS collaboration nor been penalised for failing to do so. This gives weight to the view that the dilution of corporate human rights responsibilities under the Guiding Principles acts as a barrier to compliance.[708]

Together, these findings draw attention to the limitations of the existing state-centric model as it applies to increasingly powerful technology companies,

[706] Ibid para 3; Birchall (n635) 51.
[707] Soh & Connolly (n182).
[708] Deva (n46)

exemplifying the fact that the Guiding Principles were not designed with digital companies in mind.[709] They support Wettstein's view that that Guiding Principles fail to address governance gaps between commercial actors' growing spheres of influence and the inability or unwillingness of states to regulate them.[710]

The DeepMind-NHS case also gives reason to question the limitations of corporate human rights responsibilities on the grounds of human rights minimalism. My analysis argued that Google's power over material resources in DeepMind-NHS generated resource asymmetries that amount to economic violations of the right to health. This is significant in light of critiques of the Guiding Principles' human rights minimalism, which suggest that the instrument fails to adequately address questions of structural power that can lead to violations of socioeconomic rights like the right to health. It implies that, even if the Guiding Principles were operationalised by Google, they may prove limited- if not ineffectual- in realising the right to health in data-driven research partnerships. This highlights the need to consider whether commercial actors like Google have right to health obligations beyond the minimal responsibilities contained in the Guiding Principles.

My research findings reveal evidence of the evolving societal role of Big Tech, which could support calls for a more general expansion of positive corporate human rights obligations. There is a strong pragmatic case for positive corporate human rights obligations, as evidenced by Google's power over material resources. The company is extraordinarily wealthy, its annual revenues exceeding the GDP of many states.[711] Furthermore, as exemplified by the company's growing influence over policymaking and research, technology companies also exercise power over

[709] Soh & Connolly (n182) 173.
[710] Ibid 166.
[711] Belinchòn & Moynihan (n543).

institutions, enabling them to become key political players in their own right.[712] This accumulation of material and political power is significant in light of the argument for imposing positive human rights obligations on commercial actors; it reinforces Aguirre's contention that powerful corporate actors are in a 'unique position' to promote socio-economic rights like the right to health,[713] and gives weight to the view that "an adequate account of responsibility that matches this reality must extend far beyond merely doing no harm".[714]

The justification for more expansive human rights obligations for tech companies is further strengthened by persuasive normative justifications relating to the societal responsibilities of Big Tech. My findings revealed that DeepMind have made efforts to engage in voluntary accountability and CSR initiatives in a bid to demonstrate their commitment to deliver public benefits. Their actions typify a broader societal movement towards 'health data entrepreneurism',[715] in which technology companies increasingly seek to position themselves not only as corporations but as socially-conscious actors committed to advancing the 'common good'.[716] DeepMind's eagerness to voluntarily engage in CSR thus signals shifting societal expectations of companies, confirming Sharon's observation that "'doing good' is becoming an inalienable – not an additional – dimension of corporate activity".[717] These evolving societal expectations of technology companies are significant in light of the principal justification for the restrictive corporate responsibilities contained in the Guiding Principles- the 'social expectation' of

[712] Prainsack (n73).
[713] Aguirre (n695).
[714] Wettstein (n676) 172.
[715] Prainsack (n73).
[716] Sharon 'When digital health meets digital capitalism...' (n41).
[717] Ibid 4.

businesses.[718] In this context, the human rights responsibilities contained in the Guiding Principles- which are limited to the corporate duty to 'do no harm'- appear unjustifiably limited and morally baseless.

Despite the pragmatic and normative justifications for positive corporate human rights obligations for Big Tech, the most promising development to strengthen the legal framework for corporate human rights obligations- the draft Treaty on business and human rights-[719] reinforces the Guiding Principles' 'human rights minimalism'.[720]

My findings- that Google's involvement in DeepMind-NHS reveals the limitations of the company's non-binding, restrictive human rights responsibilities under the Guiding Principles- highlight the need to reconsider the nature and scope of corporate human rights responsibilities in the digital age. They demonstrate how the growing institutional and material power of technology companies like Google is not tempered by the Guiding Principles, themselves the product of corporate influence and power over knowledge. These findings thus exemplify Birchall's view that laying bare different forms of corporate power helps to expose the linkages between them; in this case, that corporate power over knowledge- which led to a weakening of the scope and enforceability of the Guiding Principles- enables power over material resources and institutions that remains unchallenged by human rights commitments.[721] This reinforces the critical need for greater attention to the relationship between political economy and the BHR movement.[722]

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[718] UNHRC 'Report of the Special Representative of the Secretary-General on the issue of human rights and transnational corporations and other business enterprises, John Ruggie' (7 April 2008) A/HRC/8/5, para 54.
[719] Revised Draft (n689)
[720] Wettstein (n46).
[721] Birchall (n653) 53.
[722] Birchall (n179).

6.4. Conclusion

This chapter explored the implications of knowledge asymmetries in DeepMind-NHS for the right to health under international human rights law. The first section argued that the lack of transparency surrounding the partnership acts as a barrier to the UK state's ability to monitor and review the collaboration and thus to be held accountable for its right to health obligations in this context. Furthermore, though DeepMind Health engaged in a number of social responsibility and ethical initiatives, including establishing its own accountability and participatory mechanisms, these efforts fall short of the company's right to health responsibilities under the Guiding Principles, demonstrating that socially responsible and ethical behaviour should be conceptualised as complementary rather than equivalent to corporate human rights responsibilities. The final section argued that DeepMind-NHS laid bare the limitations of the Guiding Principles as a non-binding instrument with a restrictive focus on doing no harm, highlighting how Google's growing material and institutional power give reason to question the Guiding Principles' underlying justifications in the digital age.

My findings suggest that the kinds of knowledge asymmetries engendered by DeepMind-NHS act as a barrier to effective right to health accountability and even call into question the existing allocation of responsibilities at the state-business nexus, giving weight to the view that the involvement of commercial actors in digital health technologies raises questions of accountability.[723] Furthermore, it exemplifies how technology companies exercise power through the medium of institutions in

[723] Sekalala et al (n98).

ways that mutually reinforce their power over material resources yet are beyond the scope of existing human rights instruments, despite evidence that these activities significantly impact the realisation of the right to health.[724] This finding reinforces the need to strengthen socioeconomic rights protections in data-driven research partnerships and to reconsider the existing allocation of human rights responsibilities at the state-business nexus as they apply to increasingly powerful and profitable technology companies.

[724] Birchall (n635).

Chapter 7: Recommendations to help data-driven research partnerships advance the right to health

The two proceeding chapters interpreted my analysis of the DeepMind NHS case and its political-economic implications within the framework of the right to health under international human rights law. They revealed how resource and knowledge trade-offs underlying partnerships like DeepMind-NHS have significant implications for the realisation of the right to health. In light of these findings, this chapter considers potential solutions or ways forward, exploring the potential and limitations of the right to health framework to mitigate power asymmetries in data-driven research partnerships.

7.1. Mitigating resource asymmetries in data-driven research partnerships

7.1.1. Alternative commercial models

Since the establishment of DeepMind-NHS, the UK government has introduced a number of new policies with respect to data-driven technological innovation in the NHS, which take significant steps towards tackling the inequitable distribution of resources in data-driven research partnerships. In July 2019, the Department for Health and Social Care published a Code of Conduct for NHS data-

driven health technology- intended to "enable the development and adoption of safe, ethical and effective data-driven health and care technologies"- and a set of guiding principles to realise the benefits of NHS data.[725] These policy frameworks- though not legally binding- mark a significant step towards the UK government's realisation and protection of socioeconomic rights in data-driven research partnerships like DeepMind-NHS.[726]

While not prescribing any particular commercial model, the Code of Conduct recommends that NHS trusts "consider only entering into commercial terms in which the benefits of the partnerships between technology companies and health and care providers are shared fairly".[727] Furthermore, the guiding principles to realise the benefits of NHS data suggest that "the boards of NHS organisations should consider themselves ultimately responsible for ensuring that any arrangements entered into by their organisation are fair, including recognising and safeguarding the value of the data that is shared and the resources which are generated as a result of the arrangement".[728]

This broad guidance allows NHS trusts a number of possible alternative commercial models for data-driven research. Profit sharing offers one potential solution; the Code of Conduct implies the potential for use of this model, arguing that

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[725] Department for Health and Social Care 'Guidance: Code of conduct for data-driven health and care technology' (18 July 2019) <www.gov.uk/government/publications/code-of-conduct-for-data-driven-health-and-care-technology/initial-code-of-conduct-for-data-driven-health-and-care-technology> accessed 11 August 2020; Department of Health and Social Care 'Guidance: Creating the right framework to realise the benefits for patients and the NHS where data underpins innovation' (15 July 2019) <www.gov.uk/government/publications/creating-the-right-framework-to-realise-the-benefits-of-health-data/creating-the-right-framework-to-realise-the-benefits-for-patients-and-the-nhs-where-data-underpins-innovation#guiding-principles> accessed 11 August 2020.

[726] The Guiding Principles (n137) para 3.

[727] Department for Health and Social Care 'Guidance: Code of conduct for data-driven health and care technology' (n725) principle 10.

[728] Department of Health and Social Care 'Guidance: Creating the right framework to realise the benefits for patients and the NHS where data underpins innovation' (n725) principle 2.

"the participant (as data source) ... might expect to share in the increase in value".[729] Profit sharing models may better effect the realisation of socioeconomic rights by generating financial resources for NHS trusts in exchange for sharing patient data.

However, Reform's Eleonora Harwich was doubtful about the profit-sharing approach, highlighting the '*extremely technical*' nature of apportioning percentages in a fair manner. Furthermore, profit-sharing models not only fail to address the fundamental inequities between NHS trusts but may in fact fuel an internal market in the NHS, widening the gap between well-resourced, technologically-advanced trusts who are able to profit from such collaborations and those who are not. This issue has been acknowledged by the UK government; the Code of Conduct highlights the importance of determining whether a local or system-wide approach is most appropriate in developing data-driven technologies, while the guiding principles to realise the benefits of NHS data state that "NHS organisations should not enter into exclusive arrangements for raw data held by the NHS, nor include conditions limiting any benefits from being applied at a national level".[730]

Equity-sharing agreements offer an alternative model that addresses the inequities of trust-level partnership. This model is already being utilised by some NHS trusts in their research collaboration with technology company Sensyne Health.[731] In Sensyne's most recent partnership with Wye Valley NHS Trust, the Trust is set to receive a £2.5 million equity stake in the company and a share of the associated revenues, which will be fed back into the broader health system.[732] By

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[729] Department for Health and Social Care 'Guidance: Code of conduct for data-driven health and care technology' (n725) principle 10.
[730] Ibid principle 10; Department of Health and Social Care 'Guidance: Creating the right framework to realise the benefits for patients and the NHS where data underpins innovation' (n725) principle 3.
[731] 'Sensyne Health and Wye Valley NHS Trust sign Strategic Research Agreement' (28 January 2019) <www.sensynehealth.com/newsroom/sensyne-health-and-wye-valley-nhs-trust-sign-strategic-research-agreement> accessed 11 August 2020.
[732] Ibid.

delivering financial benefits at both the trust and health system levels, equity-sharing models such as this may help to incentivise NHS trusts to develop new technologies while also addressing distributive asymmetries within the health service. However, this approach doesn't challenge commercial actors' exclusive patent rights over algorithmic technologies, which would therefore pose a continued risk to the financial accessibility of data-driven technologies under the right to health.

To this end, IP-sharing agreements are a further possible alternative commercial model to DeepMind-NHS. In our interview, Hal Hodson hypothesized about the possibility of IP-sharing agreements:

"What might help is if you licensed the data to DeepMind with an agreement that gave kickback to the NHS. Say the DeepMind datasets that they've got, and one of them produces this incredible thing that no one has ever found before. Say you can stop people from dying and it becomes the basis of the medical economy around the planet and it generates trillions of dollars of revenue. Why can't the Royal Free have 0.1% of the revenue generated from that product?"

The use of IP-sharing agreements would acknowledge the collective and cumulative nature of data-driven innovation and reward the public sector accordingly, helping to mitigate the data extractivist paradigm in which all scientific and commercial benefits are rewarded to technology companies.[733] From a right to health perspective, they therefore offer the most preferable commercial model, as they both maximise the health systems' resource returns and prevent commercial actors from blocking access to any scientific and health benefits.

[733] Marianna Mazzucato (n39).

Despite these potential benefits, the Department of Health appears to dismiss this possibility in the Code of Conduct, arguing that "the participant (as data source) in a particular application cannot hope to own the underlying algorithm".[734] Though its justification is unclear, the UK government's resistance to IP-sharing agreements suggests the likelihood of their widespread use in the NHS is limited.

Further to this, multiple interviewees highlighted how the lack of commercial and data governance expertise across the NHS was a significant barrier to the establishment of data-driven research partnerships in the public interest. Professor Julian Huppert argued that the NHS was not "*currently competent to make the best deals and secure the best arrangements to get things right*", while another interviewee argued that the NHS would benefit from "*a more joined up approach, more technological know-how and more legal know-how*". Their concerns echo the comments of the Special Rapporteur on the Right to Privacy in the Digital Age who- on completion of his mission to the UK- remarked how the decentralised nature of the NHS and the inexperience of some trusts prevented the establishment of an effective partnership with DeepMind Health.[735]

In addition to these practical barriers, though alternative commercial models for data-driven research might ensure that individual partnerships contribute towards the progressive realisation of the right to health, they do not fundamentally challenge the underlying political economy of data-driven innovation, in which data is treated as a commodity that can be legitimately assetized and commercialised by state or corporate actors without the knowledge or consent of data subjects. This is problematic given mounting calls within the human rights community for scholars to

[734] Department for Health and Social Care 'Guidance: Code of conduct for data-driven health and care technology' (n725) principle 10.
[735] UN OHCHR 'End of Mission Statement of the Special Rapporteur on the Right to Privacy at the Conclusion of his Mission to the United Kingdom of Great Britain and Northern Ireland' (n83).

engage substantively with issues of political economy that constrain the realisation of socioeconomic rights.[736] To do so requires a more radical reimagination of the health data economy and its governance, to which I will now turn my attention.

7.1.2. Alternative data governance models

Data trusts- a term referring to "a legal structure that provides independent stewardship of data"-[737] offers one possible alternative to commercial partnership models in data-driven innovation. Data trusts may be a particularly promising data governance model for the NHS as they have gained significant traction in the UK in recent years, with initial pilot studies of the model receiving support from the UK Government Office for AI and Innovate UK.[738]

One interviewee described the concept in more detail:

"The Open Data Institute has been asked to come up with a practical way of going about the creation, maintenance and use of data trusts. We don't know what these data trusts will look like yet but the idea is that you have some sort of overseer and responsibility for the use of data is taken away from the individual patient or the individual hospital to the data trust. Whether the data trust is a community of people, whether it's the NHS itself... it's completely unknown at the moment and there's lots of different ideas about this."

[736] Birchall (n179); Kapczynski (n180).
[737] Open Data Institute 'Data Trusts summary report' (April 2019) <http://theodi.org/wp-content/uploads/2019/04/ODI-Data-Trusts-A4-Report-web-version.pdf> accessed 11 August 2020, 2.
[738] Jack Hardinges, 'Data trusts in 2020' (2020, ODI) available at < https://theodi.org/article/data-trusts-in-2020/ > (accessed 21 June 2021).

The data trust model offers a number of potential benefits; it gives individuals greater control over their data- enabling patients to steer data-driven health research towards their own needs- and ensure that the benefits of health data "are distributed more widely, ethically and equitably".[739] Data trusts may thus provide an alternative form of health data governance that more effectively advances the right to health than data-driven research partnerships like DeepMind-NHS.

Other data governance models like data cooperatives may also prove a more effective mechanism to advance the right to health in data-driven research. Data cooperatives are "cooperative organisations (whatever their legal form) that have as their main purpose the stewardship of data for the benefit of their members, who are seen as individuals (or data subjects)".[740] In a data cooperative, the individuals responsible for stewarding data act in the collective interests of the cooperative's members, either by advancing the interests of all members at once or achieving consensus over whether an action is permitted.[741]

The data cooperative approach is intended to give its members greater control over their data. Furthermore, by creating new, cooperatively governed data assets, data cooperatives tend to place emphasis on the use of data as a resource, opening up new opportunities for data use.[742] In light of my argument that states should pay greater attention to health data as a resource to advance the right to health, this model could therefore help to support the realisation of the right to health in data-driven health research.

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[739] Ibid 4.
[740] Ada Lovelace Institute, 'Data cooperatives' (2021, Ada Lovelace Institute) available at < https://www.adalovelaceinstitute.org/feature/data-cooperatives/ > (accessed 21 June 2021).
[741] Ibid.
[742] Ibid.

Data commons is yet another alternative form of data governance that bears much likeness to the cooperative model. There is a lack of consensus around the exact definition of data commons; however, the idea is frequently associated with 'open data' and the notion that data should serve the common good.[743] Such models often involve the pooling of data sources to generate a 'common-pool resource'; a collectively-governed, often publicly-available dataset to aid scientific research. Efforts to generate data commons resources abound; Google itself has also developed a data commons resource of open source datasets.[744] Data commons such as this promise to advance collective control over data as a means of mitigating power asymmetries in data-driven research;[745] they may thus offer a more effective means to realise the right to health and science by challenging the commercialisation of health data and its benefits.

Despite this, some critical data scholars have warned of the limitations of data commons models. Prainsack argues that not all data commons models are appropriate to address power asymmetries, as many necessitate exclusion; as such, the conflation of data commons with open data risks conversely reinforcing power asymmetries in data-driven research in health rather than mitigating them.[746] Taylor and Purtova highlight the need for greater attention to be paid to stakeholdership and governing institutions in health data commons for this model to succeed in addressing power asymmetries in health research.[747] The ability of data commons models to facilitate the realisation of the right to health may thus depend on the

[743] Prainsack (n69).
[744] 'About Data Commons' available at < https://www.datacommons.org/about > accessed 11 July 2021.
[745] Tamar Sharon & Federica Lucivero 'Introduction to the Special Theme: The expansion of the health data ecosystem – Rethinking data ethics and governance' (2019) Big Data & Soc 6(2).
[746] Prainsack (n69).
[747] Linnet Taylor & Nadezhda Purtova 'What is responsible and sustainable data science?' (2019) Big Data & Soc 6(2).

particularities of the different forms of data commons, and their stakeholders and governance.

The development of alternative commercial and health data governance models highlights the potential for the UK government to mitigate the distributive asymmetries arising from data-driven research partnerships like DeepMind-NHS and ensure that future data-driven research initiatives promote the realisation of the right to health. While alternative commercial models are currently more accessible to NHS trusts than novel data governance models, the promise of these more radical, downstream interventions- which pose a more fundamental challenge to the political economic structures that perpetuate distributive asymmetries in the data economy- justifies further development and investment by the UK government.

The distributive asymmetries and right to health implications of data-driven research partnerships like DeepMind-NHS and the potential of alternative models reveals the complex interaction between different modes of governance and the political economy of health data, highlighting how data governance has significant implications for the realisation of socioeconomic rights. This points to the critical need for the UK government to ensure that the regulatory and governance frameworks surrounding health data acknowledge and embed the full range of human rights, not just civil and political rights like the right to privacy. Despite this, innovative data governance models like data trusts, cooperatives and commons- which allow data holders greater autonomy over how their data is used- could also advance civil and political rights like the right to privacy, exemplifying the interdependencies of human rights in the digital age. Adopting a more holistic approach to health data governance that protects all human rights would satisfy the

Committee on Economic, Social and Cultural Rights' calls for states to "regulate the ownership and control of data according to human rights principles".[748]

7.2. Mitigating knowledge asymmetries in data-driven research partnerships

7.2.1. Improving transparency

To mitigate the transparency deficit surrounding data-driven research partnerships and ensure it fully discharges its obligations to respect and protect the right to health, the UK government should consider developing a comprehensive database of data-driven research partnership agreements, akin to the use of clinical trials databases in the pharmaceutical sector. This database could be compiled and updated by a centralised body like NHSX- the recently-established NHS unit tasked with driving digital transformation in the health service- which should be given powers to regularly review their progress towards advancing the right to health.

However, my analysis of the political economy of DeepMind-NHS highlighted how commercial confidentiality laws prevented the disclosure of many of the financial details of the partnership. This is problematic as this kind of information is critical to assessing the true value and distributive effects of data-driven research collaborations and their implications for the right to health. Commercial secrecy may therefore pose a more persistent barrier to effective state oversight and thus to the

[748] CESCR General Comment 25 (n87), para 76.

fulfilment of the UK government's right to health obligations under international human rights law. This supports the view that "states have a duty to develop reliable and publicly accountable information systems" and reinforces human rights scholars' calls to reframe access to data about health research as an integral component of the right to health.[749]

7.2.2. Strengthening administrative accountability mechanisms

7.2.2.1. Right to health accountability mechanisms

The UK government could further improve right to health accountability in data-driven research partnerships by strengthening accountability mechanisms in this context. An accountability mechanism is "the procedure through which government is answerable for its acts or omissions in relation to right to health obligations".[750] Accountability relies on the establishment of accessible, transparent and effective accountability mechanisms.[751] There are broadly five types of accountability mechanism; judicial, quasi-judicial, administrative, political and social.[752]

Judicial accountability mechanisms for the right to health exist at national and regional levels. The right to health is justiciable in approximately 40% of States worldwide.[753] Furthermore, all three regional human rights courts provide judicial accountability for the right to health; the European and Inter-American Courts of

[749] Lemmens & Telfer (n644) 63.
[750] Ibid 17.
[751] Potts (n109).
[752] General Comment 14 (n46).
[753] Colleen M. Flood & Aeyal Gross 'Litigating the Right to Health: What Can We Learn from a Comparative Law and Health Care Systems Approach?' (2014) Health Hum Rights 16 62-72.

Human Rights have been particularly active in this area.[754] Some countries with a justiciable right to health- such as Colombia- risk undermining health system equity and diverting resources away from those in need due to a high volume of health rights litigation.[755] As such, right to health scholars have highlighted the need for adjudication of the right to health to focus on systemic inequities as opposed to individual rights claims.[756]

Accountability can also be enforced through both specific and non-specific quasi-judicial mechanisms. At the national level, National Human Rights Institutions (NHRIs) are independent bodies established with the specific mandate of advancing and defending human rights, ranging from human rights commissions to human rights ombudsmen and public defenders.[757] However, only a small minority of the 100 existing NHRIs in the world actively engage in work on economic, social and cultural rights- fewer still on the right to health- and most lack the necessary legal mandate to effectively enforce accountability.[758] General national quasi-judicial mechanisms include patients' rights commissions or tribunals, healthcare commissions, and health complaints tribunals, autonomous bodies with varying powers and mandates.[759]

At the international level, both United Nations Committee Treaty Bodies and Special Procedures provide quasi-judicial right to health accountability. The CESCR is the main treaty body responsible for enforcing the right to health, which requires states to submit regular reports documenting their progress in implementing the right

[754] Potts (n109).
[755] Flood & Gross (n753).
[756] Lynn P. Freedman 'Human rights, constructive accountability and maternal mortality in the Dominican Republic: a commentary' (2003) Int J Gynecol Obstet 82 11-114; Alicia E Yamin 'Beyond compassion: The central role of accountability in applying a human rights framework to health' (2008) Health Hum Rights 10(2) 1-20; Flood & Gross (n753).
[757] Potts (n109).
[758] Yamin (n756).
[759] Potts (n109).

to health to which the Committee responds by making recommendations. Quasi-judicial accountability is further operationalised by the Special Rapporteur on the Right to Health, who is mandated to undertake missions, investigate human rights allegations and report periodically to the UN Human Rights Council and the General Assembly on right to health issues.[760]

Administrative right to health accountability necessitates the monitoring and evaluation of health administrative management and the establishment of administrative procedures through which individuals can bring complaints.[761] These might take the form of general administrative mechanisms, which operate at the hierarchical and horizontal levels, and supervisory bodies dealing with specific issues.[762] The complexities of administrative systems can result in multiple governmental entities having overlapping responsibilities, meaning governmental bodies at the highest level must demand accountability from other organs and non-governmental actors.[763] Furthermore, administrative accountability mechanisms require transparency around budgets, regulations and targets to facilitate the assessment of progressive realisation of the right to health.[764]

Political right to health accountability mechanisms include parliamentary committee review, democratically elected health councils and commissions, and free and fair elections.[765] As they depend on a democratic political framework, they vary from country to country.[766] Parliamentary committees conduct enquiries into specific policy issues, proposed legislation or government activities.[767] Health councils are

[760] Ibid.
[761] Qiu & MacNaughton (n158).
[762] Ibid.
[763] Ibid.
[764] Ibid.
[765] Potts (n109).
[766] Qiu & MacNaughton (n158).
[767] Potts (n109).

statutory bodies with variable powers, which may include the ability to enforce the accountability of health professionals.[768] Finally, free and fair elections can be an important retrospective political accountability mechanism, enabling the public to remove policy-makers from office when they fail to implement electoral promises.[769]

Social accountability mechanisms for the right to health rely on citizen action; they include social mobilisation, civil society movements, and the use of media to hold governments to account.[770] Although they are generally considered weaker than other mechanisms as they lack direct enforcement, social accountability mechanisms have a critical role to play where other forms of accountability are weak, where they can act as quasi-official agents or strengthen other forms of accountability.[771]

7.2.2.2. The relative weakness of right to health accountability mechanisms

DeepMind-NHS highlighted the importance placed on the right to privacy in data-driven research partnerships and the effectiveness of relevant accountability mechanisms in monitoring, reviewing and remedying violations of the right to privacy in the UK. The investigative work of Hal Hodson played a critical role in exposing the controversies associated with the Royal Free deal, generating a wealth of public and civil society interest in the collaboration and its privacy breach. This further catalysed the Information Commissioner's Office's investigation of the partnership, its ruling

[768] Potts (n109); Qiu & MacNaughton (n158).
[769] Potts (n109).
[770] Potts (n109); Qiu & MacNaughton (n158).
[771] Ibid.

that the Royal Free had breached the Data Protection Act 1998, and its request that the trust take remedial action. Other relevant bodies such as the National Data Guardian subsequently made significant efforts to strengthen privacy in health data governance.[772] The DeepMind-NHS case even drew attention at the international level from the Special Rapporteur on the Right to Privacy in the Digital Age.[773] Together, these developments demonstrate the relative strength of the accountability architecture for the right to privacy in the UK, which includes well-developed and interdependent accountability mechanisms.

By comparison to the right to privacy, accountability mechanisms for the right to health in this context are weak. The media can play an important role in holding governments accountable for the right to health, as demonstrated by the impact of the South African media's reporting and mobilisation of the public in the Minister of Health vs. Treatment Action Campaign case.[774] However, the media reports surrounding the DeepMind-NHS partnership focused predominantly on the privacy and data protection breaches associated with the Royal Free scandal and DeepMind's close connections to Google.[775] Furthermore, privacy-focused civil society organisations like MedConfidential and Open Rights Group were vocal in their scrutiny of the DeepMind-NHS collaboration; organisations explicitly concerned with the human right to health, by contrast, were absent from the debate. This lack of

[772] National Data Guardian 'National Data Guardian for Health and Care 2017 report: Impact and influence for patients and service users' (12 December 2017) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/668729/NDG_Progress_Report_FINAL_v1.1.pdf> accessed 11 August 2020.
[773] UN OHCHR 'End of Mission Statement of the Special Rapporteur on the Right to Privacy at the Conclusion of his Mission to the United Kingdom of Great Britain and Northern Ireland' (n83).
[774] Minister Of Health v. Treatment Action Campaign (TAC) (2002) 5 SA 721 (CCSA). See also Potts (n109).
[775] See Hodson (n11); Stokel-Walker (n541); Basu (n5).

social accountability reflects the lack of public awareness and political support for the right to health in the UK.[776]

Political accountability mechanisms also fail to provide accountability for the right to health in data-driven research partnerships. The Joint Committee on Human Rights (JCHR) is yet to address the issues raised by data governance and new technologies for socio-economic rights and other relevant parliamentary committees- such as the Health and Social Care Committee and the AI Select Committee- have not explicitly recognised the right to health in their work. Quasi-judicial mechanisms also predominantly fail to address the implications of data-driven technologies for the right to health; though the Equality and Human Rights Commission (EHRC)- Great Britain's statutory, independent national human rights institution- does report on the right to health, it has only addressed issues relating to data and data-driven technologies in the context of the right to privacy.[777] Furthermore, the Special Rapporteur on the Right to Health is yet to give sustained attention to data-driven innovation or AI. Judicial accountability for the right to health is also weak in the UK, as the right to health is excluded from the Human Rights Act 1998 and is thus not justiciable in UK courts.

The DeepMind-NHS collaboration also revealed the inadequacies of administrative right to health accountability mechanisms in the UK. Prior to the establishment of NHSX in April 2019, data-driven research partnerships were only subject to administrative scrutiny in relation to data protection, research ethics and health outcomes, to the exclusion of broader human rights concerns. This is

[776] Paul Hunt 'How to advance social rights without jeopardising the Human Rights Act 1998' (2019) Political Q 90(3) 393-401.
[777] See Charles Raab & Benjamin Goold 'Protecting information privacy' (2011) Equality and Human Rights Commission Research report No. 69 <www.equalityhumanrights.com/sites/default/files/research-report-69-protecting-information-privacy.pdf> accessed 11 August 2020.

reflected in the due diligence procedures surrounding the partnership, which did not include a human rights impact assessment. This is problematic not only for the UK government's accountability for the right to health but also its duty to protect the right to health under the Guiding Principles, which encourage states to ensure that commercial actors implement human rights due diligence procedures.[778]

This relative weakness of right to health accountability mechanisms in data-driven research partnerships reflects the concerns of right to health scholars that socioeconomic rights like the right to health have been relatively marginalised in the UK.[779] It further provides evidence for the continued neglect of the broader socio-economic impacts of emerging technologies and associated data practices by comparison to the direct risks they pose to values like privacy.[780] In light of my findings that data-driven research partnerships may infringe upon the right to health, this points to the urgent need to strengthen relevant accountability mechanisms.

7.2.2.3. Strengthening administrative mechanisms

There are a number of opportunities to strengthen right to health accountability in data-driven research partnerships in the UK. Unlike other quasi-judicial mechanisms, the CESCR has made significant progress in addressing the connections between emerging technologies and socio-economic rights like the right to health; General Comment 25 obligates states to "adopt policies and measures that expand the benefits of these new technologies while at the same time reducing their

[778] Guiding Principles (n137) para 3.
[779] Hunt (n776); Ellie Palmer 'Judicial review, socio-economic rights and the Human Rights Act' (Bloomsbury Publishing, 2007).
[780] Swierstra & Molder (n43)..

risks" and highlights the importance of regulating the ownership and control of data in accordance with human rights principles.[781] Further to this, the Committee will continually monitor the impact of emerging technologies on socio-economic rights like the right to health.[782] This suggests that quasi-judicial mechanisms may have an increasingly important role to play in socioeconomic rights accountability in partnerships like DeepMind-NHS.

In the UK, a number of relevant administrative mechanisms have also recently been established, notably NHSX. The new joint NHS unit for data-driven innovation has an expansive mandate, including setting national policy for NHS data-sharing, developing best practice guidelines and reforming NHS technology procurement.[783] Furthermore, the unit has committed to establishing a Centre of Expertise to "provide specialist commercial and legal advice to NHS organisations entering data agreements, develop standard contracts and guidance, and ensure that the advantages of scale in the NHS can deliver benefits for patients and the NHS".[784] NHSX is thus set to play an important future role in enforcing new NHS data governance policies like the Department of Health's Code of Conduct and guiding principles, providing much needed state oversight of the commercial aspects of data-driven research collaborations and potentially strengthening right to health accountability in this context. Despite this, the body has no statutory powers, which will likely restrict its authority.

The Centre for Data Ethics and Innovation, an independent advisory board mandated to investigate and advise the government on how to maximise the benefits

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[781] UN CESCR General Comment 25 (n87) para 74 & 76.
[782] Ibid para 74.
[783] 'What we do' <www.nhsx.nhs.uk/about-us/what-we-do/> accessed 11 August 2020.
[784] Department of Health and Social Care 'Guidance: Creating the right framework to realise the benefits for patients and the NHS where data underpins innovation' (n730).

of the data-driven technologies in the UK, is another key development in this space. The Centre for Data Ethics and Innovation has expansive powers of monitoring and review, providing overview of and insight into opportunities and risks, reviewing existing regulatory and governance frameworks, and articulating best practice for the responsible use of data-driven technology.[785] It thus affords an important opportunity to strengthen administrative accountability for the right to health in data-driven research.

Another relevant development is the part government-funded Understanding Patient Data initiative, which is mandated "to support conversations with the public, patients and healthcare professionals about how health and care data is used".[786] Though the initiative has not explicitly discussed the right to health, it indirectly enforces a key component of the right to health under the CESCR General Comment 14 by facilitating public participation;[787] this is significant given the importance of participatory systems to the protection and fulfilment of human rights in commercial data-driven health research.[788] The potential of new administrative mechanisms reaffirms Hunt's suggestion that administrative accountability may offer the best hope for advancing socio-economic rights in the UK.[789]

These findings suggest that quasi-judicial and administrative bodies have an important role to play in right to health accountability in this area. The CESCR might consider developing more detailed, specific guidance with respect to the relationship between health data governance and innovation and right to health. Furthermore, to

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[785] Department for Digital, Culture, Media and Sport 'Introduction to the Centre for Data Ethics and Innovation' (20 March 2019) <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/813933/Intro_to_CDEI.pdf> accessed 11 August 2020.
[786] 'Homepage' <https://understandingpatientdata.org.uk> accessed 11 August 2020.
[787] General Comment 14 (n46) para 11.
[788] Dove & Özdemir (n86).
[789] Hunt (n776).

strengthen general administrative mechanisms for right to health accountability, the UK government should provide support to relevant administrative bodies and encourage them to operationalise the right to health in their policies and procedures.[790]

7.2.3. Implementing human rights due diligence in data-driven research partnerships

The UK government could further mitigate knowledge asymmetries in data-driven research partnerships by implementing appropriate human rights due diligence processes. Both the Guiding Principles on Business and Human Rights and the CESCR's General Comment 24 have emphasised the importance of states promoting the corporate duty to respect human rights in commercial transactions like public sector procurement, which may provide "unique opportunities to promote awareness of and respect for human rights by those enterprises, including through the terms of contracts, with due regard to States' relevant obligations under national and international law".[791] Furthermore, CESCR's General Comment 25 requires states to "establish a legal framework that imposes on non-State actors a duty of human rights due diligence, especially in the case of big technology companies...".[792] Furthermore, under the proposed UN Treaty on Business and Human Rights, the state's human rights due diligence obligations are set to be made mandatory.[793]

[790] Knoppers et al (n88).
[791] Guiding Principles (n137), para 6; UN CESCR 'General comment No. 24 (2017) on State obligations under the International Covenant on Economic, Social and Cultural Rights in the context of business activities' (2017) UN Doc E/C.12/GC/24.
[792] CESCR General Comment 25 (n87), para 75.
[793] Bloomer & Zorob (n686).

Implementing human rights due diligence procedures is also the responsibility of companies like Google Health, who have a duty to respect human rights under the Guiding Principles on Business and Human Rights.[794]

To mitigate the absence of human rights due diligence in DeepMind-NHS, the UK government should ensure that future data-driven research partnerships are preceded by a human rights impact assessment (HRIA). As specified in the Guiding Principles, impact assessment should be undertaken periodically throughout the lifecycle of the partnership and draw upon the knowledge of both human rights experts and relevant stakeholders and affected groups, who should be placed "front and centre" in the due diligence process.[795] Technology companies should comply with these obligations, ensuring that findings from human rights impact assessments are communicated externally and integrated into company procedures and the process is repeated if further mergers and acquisitions take place.[796]

This process could be further strengthened by moving beyond the Guiding Principles' voluntarism to introduce mandatory human rights due diligence obligations for commercial actors like Google. This notion has gained traction in recent years- particularly in Europe- and may soon become reality under the proposed UN Treaty on business and human rights. At the national level, the French Corporate Duty of Vigilance Law of 2017 imposes mandatory human rights due diligence obligations on certain large companies, establishing civil liability for failure to comply.[797] Furthermore, in April 2020, the EU announced a region-wide legislative

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[794] Guiding Principles (n137).
[795] Guiding Principles (n137); John Ruggie et al 'Ten Years After: From UN Guiding Principles to Multi-Fiduciary Obligations' (2021) Business and Human Rights Journal 1.
[796] Guiding Principles (n137).
[797] Muchlinksi (n674); Gabriela Quijano and Carlos Lopez 'Rise of Mandatory Human Rights Due Diligence: A Beacon of Hope or a Double-Edge Sword?' (2021) Business and Human Rights Journal 1.

initiative to require companies in the EU to conduct human rights due diligence.[798] The draft Treaty on business and human rights also contains a mandatory due diligence requirement.[799] This growing momentum behind compulsory human rights impact assessment, if applied to data-driven research partnerships, may lead to greater consideration of human rights in future collaborations of this kind.

Despite this, even mandatory human rights due diligence can inadvertently facilitate corporate impunity for human rights violations depending on its scope, nature relationship to legal liability.[800] As such, it is critical that the application of human rights impact assessments to data-driven research partnerships prevents harm through accountability for non-compliance, is accompanied by civil liability provisions that enable rights-holders to access remedies, and ensure strong transparency and reporting duties.[801]

Oversight from an effective enforcement body is also critical. [802] In data-driven research partnerships like DeepMind-NHS, a relevant administrative body such as NHSX could fulfil this role. This demonstrates how strengthening administrative accountability mechanisms for the right to health, as I proposed in the proceeding section, could also aid in the implementation of impact assessments in this context, supporting the UK government's duty to protect and Google's duty to respect the right to health.

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[798] Quijano & Lopez (n797).
[799] UN OHCHR 'Legally Binding Instrument to Regulate, In International Human Rights Law, The Activities of Transnational Corporations and Other Business Enterprises' Second Revised Draft (6 August 2020) < https://www.ohchr.org/Documents/HRBodies/HRCouncil/WGTransCorp/Session6/OEIGWG_Chair-Rapporteur_second_revised_draft_LBI_on_TNCs_and_OBEs_with_respect_to_Human_Rights.pdf > accessed 11 July 2021.
[800] Quijano & Lopez (n797).
[801] Ibid.
[802] Ibid.

By revealing the potential impacts of data-driven research partnerships on the right to health, my research also highlights the critical need for impact assessment processes to cover *all* relevant human rights, not solely the right to privacy. This supports the views of the CESCR who, in General Comment 25, argue for the need for a holistic approach to emerging technology governance that considers all human rights.[803]

Furthermore, this finding highlights the importance of the work of right to health scholars like Williams, who has developed the first health rights impact assessment framework specifically for AI projects.[804] This framework moves beyond questions of privacy, ownership and security to consider a much wider range of issues relating to right to health principles and the impact of AI projects on the health system, including legal context, health services, goods and facilities, health workforce, health information systems, medical products, vaccines, and technologies, national financing and governance and leadership;[805] it thus gives consideration to broader questions of political economy, satisfying Birchall's calls for human rights due diligence processes to address the systemic causes of human rights infringements.[806] The UK government should therefore ensure that human rights impact assessment for data-driven research partnerships like DeepMind-NHS draw upon Williams' framework, ensuring that due diligence processes for data-driven research partnerships equally as comprehensive and prevent violations of the right to health and all other relevant rights, including the right to privacy

[803] CESCR General Comment 25 (n87).
[804] Williams (n98).
[805] Ibid.
[806] Birchall (n179).

7.2.4. Strengthening corporate right to health responsibilities

7.2.4.1. Creating binding human rights obligations for commercial actors

My findings in the previous chapter suggest there is much the UK government could do to strengthen oversight of data-driven research partnerships like DeepMind-NHS and realise its right to health obligations in this context; these include compiling a centralised, publicly-available database of existing data-driven health research partnerships and their details, supporting new administrative bodies like NHSX to operationalise the right to health in their work, and requiring human rights due diligence of technology companies in data-driven research collaborations. Existing shortcomings in the UK government's approach thus give weight to Van Ho's argument that the enforcement of existing state human rights obligations is critical to mitigating the corporate human rights accountability deficit.[807]

However, the previous chapter highlighted more fundamental barriers to the UK government holding companies like Google accountable for their human rights responsibilities, which point to the limitations of this state-centric model. Google's significant influence over policymaking and regulation, supranational operations and complex organisational structure, and disregard for regulatory efforts- including the Guiding Principles- all pose substantial challenges to states' ability to hold it accountable, highlighting how technology companies increasingly exercise power

[807] Tara Van Ho 'Band-Aids Don't Fix Bullet Holes': In Defence of a Traditional State-Centric Approach' in Jernej Letnar Černič, & Nicolás Carrillo-Santarelli (eds.) 'The Future of Business and Human Rights: Theoretical and Practical Challenges for a UN Treaty' (2018: Intersentia) 111 – 138.

over institutions and knowledge in ways that impact the realisation of human rights yet bypass existing regulatory frameworks. This suggests that efforts to persist with the Guiding Principles' state-centrism- as the proposed UN Treaty on Business and Human Rights does- may be of limited impact in addressing technology companies' human rights infringements.

This reinforces calls for the UN to consider the possibility of direct, legally-binding human rights obligations for commercial actors.[808] Numerous human rights scholars have argued for the potential benefits of adopting this approach;[809] Bilchitz, for example, proffers four justifications for legally-binding corporate obligations, including recognition of the normative position that rights impose legally-binding obligations on businesses, aligning existing law with this normative position, providing legal remedies where states cannot be held culpable and where states fail to comply with their 'duty to protect' obligations.[810] In partnerships like DeepMind-NHS, therefore, where the UK government failed to effectively discharge its duty to protect and Google shirked its non-binding responsibilities under the Guiding Principles, a legally-binding Treaty that places obligations on commercial actors could help to mitigate resulting knowledge asymmetries and lead to stronger protection of the right to health.

However, the Treaty in its current draft form does not recognise direct, legally-binding corporate human rights obligations, thus reinforcing the human rights state-centrism that characterises the Guiding Principles. Furthermore, given previous failed attempts to implement legally-binding obligations on corporate actors under

[808] Wettstein (n676); Deva (n46).
[809] Wettstein (n676); Deva (n46); Andrés Felipe López Latorre 'In Defence of Direct Obligations for Businesses Under International Human Rights Law (2020) Business and Human Rights Journal 5(51); Bilchitz (n681).
[810] Bilchitz (n681).

the Norms on Business and Human Rights and resistance to the idea both within the BHR community and from companies themselves, the feasibility of introducing legally-binding obligations for commercial actors is limited. Furthermore, in light of Google's systematic violations of other regulatory regimes, there is reason to doubt whether direct, legally-binding obligations would even prove effective in ensuring technology companies' compliance with human rights. This draws attention to the need for further investigation into the relationship between the BHR movement- including existing and future corporate human rights instruments- and today's most powerful and profitable corporate actors, Big Tech; with few exceptions, this relationship has been thus far neglected in the BHR field.[811]

7.2.4.2. Beyond human rights minimalism

The previous chapter argued that, even if Google did adhere to its human rights responsibilities under the Guiding Principles, the kinds of resource asymmetries arising from DeepMind-NHS- which act as a barrier to realisation of the right to health but do not amount to direct or egregious human rights violations- would fall outside of the Guiding Principles' focus on the duty to respect human rights and therefore would not be prevented. If the right to health is to be advanced by technology companies through data-driven innovation- or by corporate actors in any context- there is an urgent need for the human rights movement to consider the enforcement of corporate human rights obligations that extend beyond this narrow legal and ethical focus on the obligation to 'do no harm'.

[811] These include Soh & Connolly (n182) and the B-Tech Project at the Office of the High Commissioner for Human Rights (see https://www.ohchr.org/EN/Issues/Business/Pages/B-TechProject.aspx).

At the theoretical level, efforts to do so must grapple with the challenging task of determining the scope and interaction of positive state and corporate obligations; Wettstein's argument for a collaborative approach, which seeks to determine how business obligations can strengthen regulatory and public policies and contribute to the provision of goods and services, is thus a critical point of consideration.[812] Furthermore, human rights scholars have highlighted the importance of the capabilities of corporate actors in determining the extent of their positive obligations.[813] With regards to Big Tech, this approach might help ensure that the bounteous financial rewards of digital market dominance are accompanied by corresponding duties to give back to the citizens and state institutions from which these companies profit and help to mitigate emerging power asymmetries between states, citizens, and the technology giants.

These positive obligations may be operationalised through the current Treaty efforts; those stakeholders involved in the Treaty development process might thus consider the potential scope for the inclusion of positive corporate obligations. However, given the uniquely powerful position of Big Tech in the global economy, the UN might consider the potential for sector-specific obligations for technology companies. In this respect, human rights practitioners might consider ways of aligning efforts to promote positive corporate human rights obligations with current trends towards responsible research and innovation (RRI) and mission-oriented innovation in the global economy.[814] Ramasastry has highlighted the potential utility

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[812] Wettstein (n46).
[813] Jernej Letnar Černič 'An Elephant in the Room of Porcelain: Establishing Corporate Responsibility for Human Rights' in Jernej Letnar Černič & Tara Van Ho (eds) *Human Rights and Business: Direct Corporate Accountability for Human Rights* (Wolf Legal Publishers, 2015) 131-158; Wettstein (n46).
[814] For an introduction to RRI, see Richard Owen et al 'Responsible research and innovation: From science in society to science for society, with society' (2012) Sci Public Policy 39 751-760. For mission-oriented innovation, see Mariana Mazzucato 'Mission-oriented innovation policies: challenges and opportunities' (2018) Ind Corp Change 27(5) 803-815.

of providing incentives to stimulate corporate human rights fulfilment;[815] framing good corporate governance and practices through the lens of human rights advancement may thus incentivise further corporate engagement in socially-beneficial activities by strengthening their social license to operate. Developing a legal framework for positive human rights obligations could thus play a role in efforts to align public and private incentives in the global technology innovation economy.

7.2.4.3. Public function obligations

Even if the notion of expanding corporate human rights responsibilities beyond the duty to respect were not accepted, Google Health may be deemed to have positive human rights obligations under DeepMind-NHS if it qualifies as a public authority and is therefore subject to concomitant public function obligations. In his 2009 report to the Human Rights Council, Ruggie suggested that corporate obligations beyond the responsibility to respect "may be required when companies perform certain public functions",[816] though he provided no further clarity on what such responsibilities might entail. The notion of 'public function' has thus been subject to differing interpretations; Nolan and Taylor, for example, suggest that the term may apply "in a situation where... a company is exercising elements of governmental authority, or where it is acting under the instructions, direction or control of the State",[817] whereas the Institute for Human Rights and Business has

[815] Ramasastry (n117).
[816] UNHRC 'Report of the Special Representative of the Secretary-General on the issue of human rights and transnational corporations and other business enterprises' (22 April 2009) UN Doc A/HRC/11/13, para 64.
[817] Nolan & Taylor (n703) 444.

argued for greater consideration of "the scope and activities of a company and their effects".[818]

Taking forward this latter definition, the former Special Rapporteur on the Right to Health- Professor Paul Hunt- sought to determine how such public function obligations might apply to pharmaceutical companies. Hunt and Lee argued that- given the indispensable role the pharmaceutical companies play in providing access to medicines and thus fulfilling the right to health- they should be subject to additional responsibilities beyond the duty to respect human rights.[819] In 2008, in his report to the UN General Assembly, Hunt presented the Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines (hereafter the Human Rights Guidelines),[820] which aimed to provide detailed guidance about the human rights obligations of pharmaceutical companies.

The Human Rights Guidelines acknowledge that pharmaceutical companies can contribute to the realisation of the right to health in many ways, like ensuring access to medicines,[821] and that pharmaceutical companies have a set of general human rights obligations, as well as more specific duties relating to issues like transparency, accountability, patents and pricing. While some of these obligations relate to the corporate responsibility to respect, others represent additional responsibilities to protect and fulfil the right to health; for example, responsibilities to ensure the affordability of medicines and promote neglected disease research may

[818] Institute for Human Rights and Business 'Setting Boundaries: Clarifying the Scope and Content of the Corporate Responsibility to Respect Human Rights' (2009) Submission to the UN Special Representative on Business and Human Rights <www.ihrb.org/pdf/Setting_Boundaries-Clarifying_Scope_and_Content_of_Corporate_Responsibility_to_Respect_Human_Rights.pdf> accessed 15 September 2020.
[819] Lee & Hunt (n43).
[820] UNGA 'The right to health: Note by the Secretary-General' (11 August 2008) UN Doc A/63/263.
[821] Ibid Preamble I.

fall under the duty to fulfil the right to health.[822] The Human Rights Guidelines are a novel and bold effort to explicate public function obligations and to help shape corporate policies, and they have been praised by some for their specificity and innovation.[823] However, they have also faced criticism for generating a number of 'grey areas'- in which the delineation between state and corporate obligations is unclear-[824] for failing to establish direct legal obligations for pharmaceutical companies,[825] and for inadequately addressing the fundamental tension between the social obligations of pharmaceutical companies in carrying out a 'public function' and their commercial obligations to maximise shareholder value.[826]

Public function obligations have also been addressed indirectly in the CESCR General Comment 24, in which the Committee raise concerns that the affordability and quality of privatised services might be compromised in the pursuit of corporate profit-making, creating "new forms of socioeconomic segregation".[827] The Committee suggest that the state's regulatory efforts could subject commercial actors to 'public service obligations', such as "universality of coverage and continuity of service, pricing policies, quality requirements, and user participation",[828] as well as prohibitions on the denial of access to affordable and adequate services, information and treatment.[829] Furthermore, they acknowledge that particular forms of relationship

[822] Suerie Moon 'Respecting the right to access to medicines: Implications of the UN Guiding Principles on Business and Human Rights for the pharmaceutical industry' (2013) Health Hum Rights 15(1) 32-43, 41.
[823] Paul Hunt & Rajat Khosla, 'Are Drug Companies Living Up to Their Human Rights Responsibilities? The Perspective of the Former United Nations Special Rapporteur (2002-2008)' (2010) PLOS Med 7(9): e1000330; Forman & Kohler (n606) 10 & 11.
[824] Moon (n822).
[825] Grover et al (n43).
[826] Ibid.
[827] UN CESCR 'General comment No. 24 (2017) on State obligations under the International Covenant on Economic, Social and Cultural Rights in the context of business activities' (2017) UN Doc E/C.12/GC/24, para 22.
[828] Ibid para 21.
[829] Ibid.

between states and corporations- including public contracts and the corporate exercise of governmental authority- should be distinguished from other forms of corporate activity. Van Ho suggests that General Comment 24 thus employs stronger language around privatisation than previous general comments.[830]

There are two sets of criteria under which Google might be deemed a public authority under DeepMind-NHS: if the company is contracted or sanctioned by the UK state or if the effects of Google's activities play a critical and determinative role in the realisation of the right to health. The DeepMind-NHS partnership is founded on a number of contractual agreements between DeepMind/Google Health and different NHS trusts, including a Memorandum of Understanding, a research collaboration agreement, and information sharing agreements. However, these forms of contractual agreement are not legally binding and differ substantially from the kinds of public contracts used in procurement; as such, whether they qualify under the authority rationale is questionable. However, the ISA between DeepMind and the Royal Free clearly defines the roles of DeepMind as 'data processor' and the Royal Free as 'data controller', implying an authoritative relationship between state and corporation.[831] This is supported by the company's assertion that "our partners are in full control of all patient data and we will only use patient data to help improve care, under their oversight and instructions".[832] This suggests some form of authoritative public-private relationship may be established through forms of contractual agreement that differ from traditional public procurement contracts, highlighting the

[830] Tara Van Ho 'Introductory Note to General Comment No. 24 (2017) on State Obligations under the International Covenant on Economic, Social and Cultural Rights in the Context of Business Activities (CESCR)' (2019) Int Leg Matter 58(4) 872-889.
[831] Royal Free London NHS Foundation Trust 'Information Sharing Agreement' (n3)
[832] King (n545).

need for human rights practitioners to consider how novel forms of PPP may necessitate the imposition of public function obligations.

However, the activity rationale provides a more conclusive justification for Google's positive human rights obligations under DeepMind-NHS. This rationale has been theorized and operationalised in the context of the right to health by former Special Rapporteur on the Right to Health, Paul Hunt, who argued that pharmaceutical companies play an indispensable role in providing access to medicines and realising the right to health and thus qualify under the activity rationale for public function obligations.[833]

My findings suggest that technology companies like Google are set to play an ever-more critical role in providing access to data-driven health technologies, which are increasingly indispensable to the provision of quality health care services. Furthermore, my findings illustrate how the effects of Google's activities- such as their patent claims and pricing policies- have repercussions for resource availability and economic accessibility under the right to health. This suggests that technology companies like Google could qualify as public authorities under the activity rationale and may therefore be subject to additional right to health obligations under international human rights law.

The exact nature and scope of Google Health's public function obligations in the DeepMind-NHS partnership are unclear. However, given the close synergies between the pharmaceutical and data-driven technology sectors, the Human Rights Guidelines for Pharmaceutical Companies provide a useful blueprint.[834] Three

[833] UNGA (n644).
[834] Ibid.

components of these guidelines are particularly pertinent here: patents and pricing, transparency and accountability.

The Guidelines state that "pharmaceutical companies should not seek to limit, diminish or compromise the 'flexibilities' and other features of the intellectual property regime that are designed to protect and promote access to existing medicines",[835] and that a pharmaceutical company "should consider all the arrangements at its disposal with a view to ensuring that its medicines are affordable to as many people as possible".[836] In the context of Google's partnership with the NHS, these principles would require the company to refrain from establishing exclusive patent rights over algorithmic technologies developed in collaboration with the public sector, to agree a cap on prices across the NHS, or to actively consider ways to facilitate financial accessibility through technology donation or financing programmes.

Furthermore, the importance of transparency in facilitating access to medicines is continually emphasised throughout the Guidelines; Hunt recommends that companies agree to "standard formats for systematic disclosure of information and data bearing upon access to medicines",[837] including financial information- such as information relating to drug pricing, drug donation, patients treated, and tax benefits- and information about political activities like advocacy and lobbying. Applying these conditions to data-driven research partnerships implies that companies like Google should make commercial information relating to their patent applications, technology pricing, and political activities publicly available, further reinforcing to right to health case against commercial secrecy.[838]

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[835] Ibid.
[836] Ibid para 33.
[837] Ibid para 7.
[838] Lemmens & Telfer (n644)

The Guidelines also obligate companies to establish an independent body to monitor disputes regarding information on access to medicines, develop a publicly available policy on access to medicines, and establish direct, board-level responsibility for access to medicines, as well as publishing an annual report to facilitate monitoring and accountability.[839] Each company should also "encourage and facilitate multi-stakeholder engagement in the formulation of its policies, programmes, projects and other activities that bear upon access to medicines".[840] In the context of DeepMind-NHS, Google could integrate considerations around access to technologies into monitoring and review and policy and decision-making processes, as well as engaging more stakeholders in these processes.

Though I have argued the case for technology companies having public service obligations in data-driven health research partnerships like DeepMind-NHS, the voluntary nature of the Guidelines for Pharmaceutical Companies calls into question the effectiveness of existing efforts to enforce public service obligations. My findings have pointed to the limitations of voluntary regulatory efforts in the face of shareholder interests; in this context, Hunt's contention that companies should take reasonable steps to improve access to medicines "within a viable business model" casts doubt on the willingness and ability of commercial actors to enact public service obligations.[841] This is supported by evidence that pharmaceutical companies have continued to engage in practices that infringe upon the right to health after the publication on the Human Rights Guidelines, including insufficiently differentiated prices within and between countries, lack of attention to neglected diseases, lack of disclosure of financial support from political candidates, inappropriate drug promotion

[839] UNGA (n644)
[840] Ibid para 9.
[841] Lee & Hunt (n43) 228.

and problematic clinical trials.[842] Thus, despite their voluntary nature, the Human Rights Guidelines failed to obtain support from industry; at a UN sponsored expert consultation on access to medicines and the right to health in 2010, none of the invited pharmaceutical companies participated.[843]

This reinforces calls for stronger accountability for corporate actors carrying out public functions.[844] Furthermore, the proliferation of novel forms of PPP in the field of health calls for human rights advocates to pay greater attention to public function obligations and their potential applications.

7.3. Conclusion

This chapter summarised my recommendations to advance the right to health through data-driven research partnerships. The first section of the chapter discussed ways to mitigate resource asymmetries in future data-driven research partnerships. Firstly, it explored the potential of alternative commercial data-driven innovation models, including profit, equity and IP sharing models. In light of their limitations in addressing questions of underlying political economy, it turned to the possible benefits of more radical data governance approaches such as data trusts, cooperatives and commons, which more fundamentally challenge the resource asymmetries associated with the political economy of data-driven innovation.

The second section of the chapter explored solutions to improve the distribution of knowledge in data-driven research partnerships. Firstly, it argued for

[842] Hunt & Khosla (n823) 3.
[843] Ibid.
[844] Grover et al (n43).

the need for a centralised, publicly-accessible database of data-driven research partnerships to improve transparency and facilitate monitoring and review. It then drew attention to the weakness of right to health accountability mechanisms in DeepMind-NHS, making the case for strengthening quasi-judicial and administrative mechanisms in this context. The following section argued for the need to strengthen human rights due diligence in data-driven research partnerships, ensuring that impact assessments are inclusive of the right to health. The final section reflected on the limitations of existing corporate right to health responsibilities, arguing that protecting the right to health in data-driven research partnerships requires binding corporate right to health obligations that extend beyond the duty to 'do no harm' and considering how the precedent of public function obligations may provide an opportunity to strengthen corporate right to health accountability in this context.

These recommendations attempt to address the underlying political economy of data-driven research partnerships and its detrimental impacts on the right to health, thus reflecting a vision of international human rights law that challenges the logics and institutions neoliberalism in the digital age. They therefore respond to human rights scholars' calls to consider the broader political economic conditions under which the possibilities for the realisation of socioeconomic rights like the right to health are determined, reinforcing the centrality of questions of political economy in human rights.[845]

These recommendations also move beyond the protection of privacy in the governance of data and technology to consider ways to mitigate the broader, systemic impacts of data-driven innovation on health systems. In this respect, they

[845] Kapczynski (n180); Lisa Forman, 'Is the right to medicines a canary in the human rights coalmine?' (2019) Humanity Journal available at < http://humanityjournal.org/blog/is-the-right-to-medicines-a-canary-in-the-human-rights-coalmine/ (accessed 21 June 2021); Birchall (n635).

build upon the work of the small body of socioeconomic rights scholars who have sought to expand the conversation around the relationship between data, technology and human rights beyond the narrow range of civil and political rights that remain the predominant concern of policymakers in this area. In doing so, this chapter supports the view that "not only should digital health technologies ensure privacy, but they should be leveraged to advance the right to health in an equitable, non-discriminatory manner".[846]

[846] Sun et al (n98) 29.

Chapter 8: Conclusions

8.1. Research Aims

This section summarises my findings in relation to my three research aims: a. To analyse the political economy of the DeepMind-NHS partnership, with a particular focus on the distribution of resources and knowledge; b. To explore the implications of the political economy of the DeepMind-NHS partnership for the right to health; c. To consider how future data-driven research partnerships like DeepMind-NHS can advance the right to health.

8.1.1. The DeepMind-NHS case: implications for political economy

My in-depth analysis of the DeepMind-NHS case and its political-economic implications first assessed the promise of the partnership. I argued that the Memorandum of Understanding between DeepMind and the NHS, as well as public statements about the collaboration, suggested it would be mutually beneficial for both parties; proposed benefits to the NHS and its patients included improved efficiency of the healthcare system, better quality of care, and the development of new innovations in healthcare. This exemplifies how- much like other PPP models- data-driven research partnerships like DeepMind-NHS are justified on the basis that they deliver mutual benefits.[847] I further argued that DeepMind's blue-sky mission

[847] Hodge & Greve (n39).

statement, leadership, public engagement work, development of an Independent Review Panel and engagement with CSR have created a public image of the company as a socially-conscious, publicly accountable research organisation motivated by societal benefit as opposed to commercial objectives. This image supports the view that PPPs can afford an opportunity for improved transparency and accountability in the delivery of public goods and services, highlighting how engagement with CSR and contributing towards the greater good has become a critical characteristic of technology corporations.[848]

Despite the promise of DeepMind-NHS, my analysis further revealed asymmetries in the distribution of resources between public and private sectors. The contractual agreements underlying DeepMind-NHS stated that the company would keep all IP developed through the collaboration. Thus, research partnerships like DeepMind-NHS risk facilitating the accumulation of IP- and with it entitlements to the scientific and commercial benefits of NHS patient data- in the hands of a few powerful technology companies like Google.

The contractual agreements also shared a common feature; that clauses relating to payments and the costs of Google's services were redacted, preventing the public from accessing information about the price of technologies developed under the partnership and the long-term costs of their use to the NHS. The lack of clarity surrounding pricing is problematic in light of Google's exclusive rights to developed IP, as it risks corporate price-gouging- akin to that practiced in the pharmaceutical sector- which could restrict NHS trusts' access to the innovations resulting from the collaboration. This highlights the existence of an 'innovation lottery'

[848] Hood et al (n55); Brinkerhoff & Brinkerhoff (n39); Sharon 'When digital health meets digital capitalism...' (n41).

in the NHS, such that patients in the least financially viable NHS trusts are least likely to benefit from new data-driven technologies.[849] This is further exacerbated by concomitant inequities in digital maturity between NHS trusts; as digital maturity is an important precondition to the development and implementation of data-driven technologies, this inequity risks generating new divides between data rich and data poor NHS trusts. These findings reveal how- where due consideration is not given to the broader health systems in which they are embedded- data-driven research partnerships like DeepMind-NHS may exacerbate health inequities, revealing how neoliberal reforms in the NHS- including fragmentation of the health system and the introduction of PPPs- have contributed to health inequities.

Together, these resource asymmetries highlight how the short-term incentives of access to technology for free can overshadow consideration of the long-term costs and broader impacts of data-driven research partnerships for the NHS. They demonstrate how companies like Google adopt a 'data extractivist' business model to capture scientific and commercial value through PPP.[850] My findings thus reveal the real resource trade-off necessitated by DeepMind-NHS; that underlying the rhetoric of mutual benefit is a partnership model that allocates the long-term scientific and commercial benefits- as well as the power to control access to their health applications- solely to Google. This trade-off demonstrates the vulnerabilities of the concept of value in data-driven research partnerships- which is both ambiguous in the context of health data and can be manipulated in PPPs to serve private interests- revealing political economic risks that extend far beyond privacy.[851]

[849] Thomas et al (n505).
[850] Morozov (n63).
[851] Sharon 'When digital health meets digital capitalism...' (n41); Mazzucato (n65).

Further to this, the DeepMind-NHS collaboration was only publicly announced after the original data transfer had taken place and was significantly more wide-ranging and ambitious than any public announcements had disclosed. Public knowledge of the partnership therefore heavily relied on the investigative work of journalist Hal Hodson, who himself faced challenges in interpreting the information he gathered through FOI requests. Commercial confidentiality laws were a further barrier to transparency around the partnership, enabling the redaction of prices that prevented assessment of the value of DeepMind-NHS. Furthermore, some interviewees suggested this opacity is indicative of a broader lack of transparency surrounding commercial deals in the NHS, which are not routinely subject to public disclosure. Together, these findings highlight how DeepMind-NHS has suffered from a lack of transparency that not only covered up the original data transfer- enabling a serious breach of patient privacy- but also obscured important commercial details of the collaboration, preventing public appraisal of its long-term risks and benefits.

My analysis further uncovered details of DeepMind's relationship to Google, which troubled critics from the start. DeepMind remained secretive about the business model it intended to pursue through collaboration with the NHS and publicly distanced itself from Google, resulting in a lack of clarity around their relationship. Despite this, in November 2018, DeepMind Health was subsumed under Google Health, a move that led to the abandonment of the Independent Review Panel and was justified on the basis of commercial interests. The merger demonstrated how partnerships like DeepMind-NHS can enable Big Tech's stealthy expansion into health markets, affording them ever-greater power and influence over the future of healthcare.[852] These concerns about Google's encroachment on healthcare markets

[852] Sharon 'The Googlization of health research...' (n41).

are further fueled by the company's disregard for privacy norms; its business model of 'surveillance capitalism' and involvement in numerous privacy scandals- many of which fall within the bounds of legality despite their intrusiveness- demonstrate the limited means available to the public to hold Google to account. This lack of accountability is further evidenced by Google's breaches of anti-trust and taxation laws. The company also occupies an increasingly prominent position in AI policymaking and research, which risks corporate bias in efforts to regulate the industry. These findings point to the expanding monopoly powers and lack of accountability of technology companies like Google and growing power asymmetries between commercial actors, the NHS and its patients.[853]

Together, my findings reveal the knowledge trade-off underlying DeepMind-NHS; that collaboration with a seemingly publicly-accountable and socially-responsible technology company obscures the covert expansion of the monopoly powers of Big Tech. This trade-off implies that the potential benefits of technology companies' engagement in socially-beneficial technological innovation in health may come at the cost of public accountability. It further points to the 'toothlessness' of voluntary corporate responsibility- which relies entirely on corporate good will- in the face of shareholder interests, highlighting the importance of remaining critical of the effectiveness of such initiatives and underscoring the need for robust accountability mechanisms.[854]

[853] Sharon 'When digital health meets digital capitalism...' (n41); Prainsack (n69).
[854] Vaidhyanathan (n73); Cath (n73); Nemitz (n72).

8.1.2. Resource asymmetries: implications for the right to health

This chapter analyzed asymmetries in the distribution of resources in DeepMind-NHS through the lens of the right to health. Firstly, it argued that Google's exclusive rights to any developed IP under DeepMind-NHS and the lack of clarity around future pricing may enable corporate price-gouging that restricts the accessibility and equitable provision of technologies developed under the collaboration, thus posing risks to the rights to health and science. This raises questions about the human rights responsibilities of and relationship between public health systems and commercial actors in facilitating access to technologies in data-driven research partnerships. It further highlights how intellectual property systems pose a persistent challenge to the realization of the rights to health and science.

The following section argued that the 'data extractivist' business model Google pursued through DeepMind-NHS draws attention to the increasing importance and value of health data as a public asset in the digital economy. As a result, I called for health data to be recognised as a resource to progressively realise the right to health under Article 2(1) of the ICESCR and considered some of the challenges this may present, including risks of data misuse that threaten the right to privacy. Framing health data as a resource to progressively realise the right to health under international human rights law reveals the ineffectiveness of DeepMind-NHS in leveraging the value of patient data to this effect, as all scientific, health and commercial benefits are allocated to Google. This suggests that this type of partnership does not facilitate the progressive realisation of the right to health,

casting doubt on the effectiveness of PPPs as a means to maximise the state's available resources.

The final section suggested that the promise of DeepMind-NHS to deliver public benefits highlights the potential of data-driven research partnerships to advance the right to health. Despite this, the resource trade-off underlying DeepMind-NHS instead points to a right to health paradox; that the promise of collaborating with commercial actors to advance the right to health through data-driven innovation may conversely present barriers to its effective realisation, This conclusion draws attention to the way that neoliberal policies- including the expansion of IP systems, the fragmentation of health systems, and the introduction of PPP governance models- generate a political economic reality that constrains the realization of the right to health, supporting Birchall's view that economic violations by commercial actors pose substantial risks to the right to health.[855] It further demonstrates how the distributive requirements of the right to health have evolved in the data economy, highlighting the need to reinterpret the international human rights framework in the context of the digital economy and for the UK government to consider alternative data governance models that mitigate digital divides and leverage the value of health data as a public asset.

8.1.3. Knowledge asymmetries: implications for the right to health

[855] Birchall (n635).

This chapter explored the implications of knowledge asymmetries in DeepMind-NHS for the right to health under international human rights law. The first section argued that the lack of transparency surrounding DeepMind-NHS acts as a barrier to the UK government's ability to monitor and review the partnership and thus the restricts the state's accountability for the right to health in this context.

The second section highlighted how, despite DeepMind Health's socially-responsible and ethical behaviour- including establishing its own mechanisms for accountability and participation- these efforts fall short of the company's right to health responsibilities under the Guiding Principles; neither DeepMind nor Google conducted a human rights impact assessment prior to establishing the partnership and any policy commitments to human rights are not adequately operationalised throughout the company. This highlights the distinction between CSR and corporate human rights responsibilities and supports the idea that technology companies should prioritise their legal responsibilities under international human rights law rather than viewing them as an adjunct to or component of their broader CSR agendas.[856]

The final section argued that Google's growing material and institutional power- as evidenced in the DeepMind-NHS partnership- poses a challenge to the Guiding Principles' restrictive focus on 'doing no harm' and their non-binding nature, laying bare their limitations in realising the right to health in data-driven research partnerships. These limitations, I argue, give reason to question the underlying justifications of the Guiding Principles in the digital age, highlighting how companies exercise power in ways that fall beyond the scope of the existing framework of

[856] Sun et al (n98) 24.

international human rights law.[857] This calls for reconsideration of the scope and legal authority of corporate human rights obligations as they apply to Big Tech.

8.1.4. Recommendations to help data-driven research partnerships advance the right to health

In light of my analysis of the right to health implications of DeepMind-NHS, this chapter summarised my recommendations to advance the right to health through data-driven research partnerships. Firstly, I explored the potential of alternative commercial data-driven innovation models as a means of mitigating resource asymmetries in data-driven research partnerships. I considered the potential benefits of profit, equity and IP-sharing models, concluding that- while all three may potentially benefit the right to health- they also are limited in their capacity to address the underlying political economy of data-driven innovation. I thus considered the potential benefits of more radical data governance approaches including data trusts, cooperatives, and commons, arguing that these models may be more effective in challenging the resource asymmetries associated with the political economy of data-driven research partnerships like DeepMind-NHS.

The second section explored solutions to improve the distribution of knowledge in data-driven research partnerships. Firstly, it argued for the need for a centralised, publicly-accessible database of data-driven research partnerships to improve transparency and facilitate the state's efforts to monitor and review the realisation of the right to health in data-driven innovation. Next, it drew attention to

[857] Birchall (n635).

the weakness of right to health accountability mechanisms in DeepMind-NHS, arguing for the need to strengthen quasi-judicial and administrative mechanisms to realise the right to health in data-driven research partnerships. Subsequently, I made the case for strengthening human rights due diligence in data-driven research partnerships, ensuring that impact assessments are inclusive of right to health concerns. Finally, I reflected upon the limitations of existing corporate right to health responsibilities, arguing that protecting the right to health in data-driven research partnerships requires binding corporate right to health obligations that extend beyond the duty to 'do no harm' and exploring how the precedent of public function obligations may provide an opportunity to strengthen corporate right to health accountability in PPPs.

By seeking to address the political economy of data-driven research partnerships like DeepMind-NHS, these recommendations reflect a vision of international human rights law that challenges the logics and institutions of neoliberalism, thus reinforcing the view that questions of political economy are intrinsic to the study and operationalisation of human rights.[858] They also move beyond privacy concerns to consider ways to mitigate the broader, systemic impacts of data-driven research partnerships in health, thus building upon the work of socioeconomic rights scholars who have sought to open up the conversation around data, technology and human rights beyond the narrow range of civil and political rights that have predominated discussions in this area.[859]

[858] Birchall (n179); Kapczynski (n180).
[859] Harris & Wyndham (n88); Davis & Williams (n98); Williams (n98); Sun et al (n98); Sekalala et al (n98).

8.2. Limitations

My research findings are subject to limitations that must be acknowledged. The first relates to the generalisability of my findings, both to other data-driven research collaborations like DeepMind-NHS and to PPPs more generally. In recent years, the NHS has entered into a number of partnerships with Big Tech, most recently with Apple and Google to develop the government's coronavirus contact-tracing app.[860] At the global level, these companies are also engaged in a multitude of data-driven research initiatives in health.[861]

There are undoubtedly comparisons to be drawn between such partnerships and the DeepMind-NHS case. However, Brinkerhoff and Brinkerhoff have highlighted the diversity of PPP purposes, structures and processes, which restrict the generalisability of any conclusions about PPPs in a particular setting.[862] In drawing upon scholarship across studies of PPPs in multiple contexts, I have attempted to draw out the commonalities between PPP models and thus to improve the generalisability of my findings. However, I acknowledge the likelihood of significant differences between the DeepMind-NHS partnership and other data-driven research collaborations. Therefore, my findings should be interpreted as exemplifying some of risks that data-driven research poses to the right to health as opposed to providing a comprehensive overview or generalisable template of these implications.

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[860] Andrew Downey 'NHS partners with tech giants to develop Covid-19 data platform' (*Digital Health*, 6 April 2020) <www.digitalhealth.net/2020/04/nhs-partners-with-tech-giants-to-develop-covid-19-data-platform/> accessed 19 August 2020.
[861] For a useful summary article, see Zoë LaRock 'BIG TECH IN HEALTHCARE: Here's who wins and loses as Alphabet, Amazon, Apply and Microsoft hone in on niche sectors of healthcare' (*Business Insider*, 30 Jan 2020) <https://www.businessinsider.com/big-tech-in-healthcare-report?r=US&IR=T> accessed 15 September 2020.
[862] Brinkerhoff & Brinkerhoff (n39) 13.

Further to this, my research has been subject to a number of practical limitations. In particular, the collection of my interview data has been necessarily restricted by the time constraints of a doctoral thesis and by the willingness and ability of private sector actors to participate in research interviews. Though my nineteen semi-structured interviews have provided a rich source of information, they cannot solely paint a representative picture of the DeepMind-NHS case. For this reason, my interview findings are best considered as a supplementary and enriching adjunct to data gleaned from analysis of grey literature.

My research has also been complicated by the unfolding of events in real-time, meaning that major developments in the case- such as DeepMind Health's merger under Google- played out during the course of my interviews and document analysis. As a result, there are inevitable inconsistencies across my documentary and interview sources, which complicated the analytical process. As best as possible, I have attempted to clearly contextualise my document analysis and interview data, such that particular references and quotes do not misrepresent the details of the case study or the views of particular authors and research participants.

8.3. Recommendations for future research

This thesis highlights a number of areas that warrant further enquiry by human rights scholars. IP regimes have serious implications for access to medicines under the right to health; however, the impact of these systems for the right to health in the area of algorithmic health technologies are yet to be fully explored. Given Big Tech's growing interests in healthcare markets and the synergies between the

issues raised by PPPs in the pharmaceutical sector and the DeepMind-NHS case, this would be a fruitful area for future research. Furthermore, though I have argued for greater state recognition of the potential utility of their data resources as a means to advance socio-economic rights like the right to health, the ethical and practical issues I raised- including the 'availability' of data, the risks of data misuse, and the difficulties of measuring state compliance- all warrant further investigation. Here, I have also begun to explore the right to health implications of different commercial and data governance models, highlighting the potential utility of human rights discourse as a means of challenging distributive data injustices; as such, future research might explore these issues in greater depth or in different sectors, ensuring that socio-economic rights are on the political agenda in the area of data governance.

My conclusions also highlighted how commercial confidentiality is an ongoing hindrance in efforts to realise the right to health, a topic that warrants further attention. Further to this, this thesis called into question the efficacy of both corporate human rights responsibilities and CSR efforts and the complex relationship between them; scholars might consider investigating the benefits and limitations of the Guiding Principles as they apply to increasingly powerful and influential corporate actors or their potential to compliment, strengthen or undermine existing governance and regulatory efforts in the technology and health sectors.

I have also called into question the legitimacy of non-binding, minimal corporate human rights responsibilities in the digital age. Building on this, future research may thus further explore the limitations and benefits of the existing state-centric, 'do no harm' model in the context of Big Tech and the potential impacts of direct, legally-binding or more expansive, positive obligations in this space. Finally,

my work highlighted the lack of clarity surrounding the concept of public function obligations in international human rights law. In light of the prevalence of PPP models around the globe in a diversity of forms, including data-driven research partnerships, there is an urgent need for the human rights community to give greater attention to this issue; future research might seek to clarify the situations in which such obligations apply- for example, what kind of contractual obligations qualify as establishing an 'authoritative' relationship- or to determine what such obligations might entail.

8.4. Key Contributions

8.4.1. Key contributions to international human rights law

By utilising the legal framework of the right to health, my analysis expands the scope of human rights scholarship on commercial data-driven health research. To date, much of the scholarship surrounding commercial data-driven health research- both within and beyond the field of human rights- has focused predominantly on privacy. Though the CESCR and some right to science scholars had highlighted the relevance of the right to health in this context,[863] socio-economic rights like the right to health remained underexplored in scholarly debate. Approaching the topic of data-driven research from the standpoint of the right to health thus responds to calls for scholarship beyond the narrow set of issues that has thus far dominated the human

[863] UN CESCR 'General comment No.25 (2020) on science and economic, social and cultural rights (article 15(1) (b), (2), (3) and (4) of the International Covenant on Economic, Social and Cultural Rights)' (n87); Knoppers et al (n88); Petersen (n95).

rights literature in this area,[864] furthering efforts "to regulate the ownership and control of data according to human rights principles" in accordance with CESCR's General Comment 25.[865]

My findings also highlight how the distributive effects of data-driven research partnerships like DeepMind-NHS implicate the state obligation to provide equitable access to technologies under the right to health, vindicating the CESCR's concerns that the involvement of commercial technology companies in the provision of algorithmic health technologies may compromise their financial accessibility and thus infringe upon the state's duty to protect. This reinforces the critical importance of IP systems for the realisation of socio-economic rights and the interdependence of the rights to science and health in the context of scientific research.[866] Furthermore, my work builds on the existing body of literature surrounding the MAR requirement under Article 2(1) of the ICESCR,[867] contextualising it in the data economy; it thus reinforces the need for an evolving conception of available resources and a renewed emphasis on their quality.

My thesis further demonstrates the limitations of the state's accountability and duty to protect the right to health in data-driven research, giving weight to scholars' calls for access to information around health research and providing evidence of the relatively weak position of the right to health in the UK.[868] It also draws comparisons

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[864] van Veen 'Artificial Intelligence: What's Human Rights Got To Do With It?' (*Points (Data and Society)*, 14 May 2018) <https://points.datasociety.net/artificial-intelligence-whats-human-rights-got-to-do-with-it-4622ec1566d5> accessed 5 August 2020.
[865] UN CESCR 'General comment No.25 (2020) on science and economic, social and cultural rights (article 15(1) (b), (2), (3) and (4) of the International Covenant on Economic, Social and Cultural Rights)' (n87) para 76.
[866] UN CESCR 'Human rights and intellectual property: Statement by the Committee on Economic Social and Cultural Rights' (n87); UN CESCR 'General comment No.25 (2020) on science and economic, social and cultural rights (article 15(1) (b), (2), (3) and (4) of the International Covenant on Economic, Social and Cultural Rights)' (n87).
[867] Skogly (n620); Robertson (n618).
[868] Lemmens & Telfer (n644); Hunt (n776).

between CSR and the Guiding Principles, contributing to a greater understanding of their differences and highlighting the limitations of their voluntarism.[869] Furthermore, by highlighting the limitations of the state-centric model of human rights law in the context of Big Tech and considering the case for positive human rights obligations for technology companies like Google, my thesis provides empirical evidence in support of normative and practical critiques of the Guiding Principles, thus contributing to the ongoing debate surrounding the nature and scope of corporate human rights obligations under the future Treaty on Business and Human Rights.[870] By elaborating on existing notions of public function obligations in international human rights law, it also builds upon Hunt's rationale for and explication of public function obligations for commercial actors in the health sector, highlighting the need for further consideration of the application of human rights law to PPPs.[871]

Historically, human rights approaches have avoided engaging with economic questions, leading some critics to claim that the human rights movement has either failed to challenge or even been complicit in the emergence and proliferation of the neoliberal economic order. [872] By directly addressing questions of political economy, the state-business nexus, and corporate power over human rights, my research builds upon the work of those human rights scholars who advance an alternative, constructive vision of human rights as a counterforce to neoliberal inequalities.[873] In doing so, it makes an early contribution to the nascent field of human rights and political economy as a distinct field of enquiry within BHR.[874] Furthermore, by reflecting upon the limitations of existing human rights instruments in countering

[869] Ramasastry (n117); Deva (n46); Cath (n73); Nemitz (n72).
[870] Deva (n46); Wettstein (n46); Wettstein (n676); UNGA (n644).
[871] UNGA (n644); Lee & Hunt (n43).
[872] Klein (n179); Marks (n179); Moyn (n179).
[873] Birchall (n179); Kapczynski (n180); Alston (n180).
[874] Birchall (n179).

neoliberalism and considering opportunities to strengthen the legal system, my work reveals human rights themselves as a site of political struggle, reinforcing the critical need for a political economy approach as "a necessary revolution within contemporary practice".[875]

8.4.2. Key contributions to the political economy of PPPs

My analysis of the political economy of the DeepMind-NHS collaboration indicated that DeepMind are set to disproportionately reap its benefits, casting doubt on the rationale underlying PPPs; that they are mutually beneficial to public and private sectors[876]. These findings contribute to the body of evidence that PPPs do not deliver tangible public benefits and calls for deeper interrogation of the claims surrounding PPP models.[877] Furthermore, this thesis argued that the DeepMind-NHS partnership suffered from an accountability deficit, giving weight to political economists' views that PPPs provide only limited opportunities for transparency and accountability.[878]

My findings also highlight how data-driven research partnerships are a yet another iteration of the PPP paradigm, which- despite its diverse forms and contexts- are united by their underlying rationales and associated risks. The commonalities between the DeepMind-NHS partnership and previous PPP models highlight the politicisation of the partnership paradigm- which evolves to suit "the political need of

[875] Ibid 28.
[876] Hodge & Greve (n39).
[877] Pollock et al (n213); Shaoul 'A critical financial analysis of the Private Finance Initiative: selecting a financing method or allocating economic wealth?' (n51).
[878] Reich (n59).

the moment"-[879] and reveal the novel forms that PPPs inhabit in the data economy. This has ramifications for policymakers in the area of health data governance, who might acknowledge and learn from previous efforts to regulate PPP models.

8.4.3. Key contributions to critical data studies

By revealing the potential for data-driven research partnerships to generate distributive injustices, my thesis contributes to a growing body of scholarship around the political economy of health data in critical data studies, providing evidence of commercial practices of data rentiership and their inequitable consequences.[880] Furthermore, by exploring the nuances of conceptions of value and benefit in data-driven health innovation,[881] this thesis reveals the trade-offs underlying the DeepMind-NHS collaboration, reinforcing the need for these to be made transparent.[882]

This thesis also gives weight to concerns about the growing power and political influence of Big Tech, exemplifying the process of the 'Googlization' of health in action.[883] It thus brings further evidence to the body of critical literature documenting Google's rise to power, expanding global monopoly, and expansion into healthcare markets.[884] By critically evaluating DeepMind's CSR efforts through the lens of human rights, my work further sheds light on the movement towards 'health data entrepreneurism' in the health technology sector,[885] highlighting the

[879] Hodge & Greve (n186)
[880] Birch et al (n40); Parry & Greenhoulgh (n68).
[881] Sharon 'When digital health meets digital capitalism...' (n41); Mazzucato (n65).
[882] Sharon 'When digital health meets digital capitalism...' (n41); Blasimme et al (n70).
[883] Sharon 'The Googlization of health research...' (n41).
[884] Ibid; Vaidhyanathan (n73).
[885] Prainsack (n69).

need to remain sceptical of voluntary governance initiatives and to push for robust governance frameworks.[886]

8.4.4. Interdisciplinary insights

The interdisciplinarity of my research has also generated novel insights into the topic of data-driven research partnerships and the three disciplinary strands this thesis synergises. By drawing on the substantial body of political economic scholarship on PPPs to explore the implications of the DeepMind-NHS partnership for the right to health, my thesis highlights how the human rights community have not adequately addressed the PPP phenomenon, as evidenced by the obscurity and lack of enforcement surrounding the concept of public function obligations in international human right law. My work thus makes an early contribution to a human rights scholarship on PPPs, highlighting the need to give greater consideration to public function obligations and building on the work of right to health scholars who have sought to justify their application and define their scope in the health sector.[887]

Furthermore, by revealing how the DeepMind-NHS collaboration allocates resources disproportionately to the private sector, my political economic analysis of the partnership called into question PPPs as an efficient and effective means of channelling available data resources towards the realisation of the right to health. This casts doubt upon the assumption that the state can make resources available for the advancement of socio-economic rights through private sector contributions like PPP.[888] To date, the majority of scholarship surrounding MAR has focused on

[886] Vaidhyanathan (n73); Cath (n73).
[887] UNGA (n644); Lee & Hunt (n43).
[888] Balakrishnan et al (n623); Skogly (n620); Robertson (n618).

financial resources and macroeconomic analysis of resource availability. By providing empirical analysis of the implications of PPP for MAR, my findings thus highlight the need for a parallel, more in-depth focus on the distributive effects of specific funding models for MAR and a potential role for political economic analysis in this context. This would provide greater nuance to discussions surrounding the role of the private sector in making resources available for the realisation of socio-economic rights, helping to guide states' policymaking efforts to this end.

Furthermore, by contextualising my right to health analysis in the political economy of health data, my research contributes to a more dynamic understanding of the right to health in the digital age and the nature of so-called 'postindustrial rights violations'.[889] In particular, it draws attention to the potential benefits of data resources as a means of progressively realising socio-economic rights under Article 2(1) of the ICESCR and the limitations of existing legal instruments enshrining state and corporate right to health obligations in the data economy. This demonstrates the utility of an interdisciplinary socio-legal approach in facilitating the continued evolution of the international human rights framework, highlight the need for the law to remain responsive to the technological, political and economic systems in which it operates.

The framework of international human rights law also has much to offer the fields of political economy and critical data studies. Brinkerhoff and Brinkerhoff have argued that PPPs can promote good governance values like human rights;[890] in such cases, they suggest, "inclusion, equity, transparency, accountability and ethical behaviours become integral to the partnership functions".[891] My right to health

[889] Soh & Connolly (n182)
[890] Brinkerhoff & Brinkerhoff (n39).
[891] Ibid 12.

analysis suggest these values are not being realised in the DeepMind-NHS partnership; thus, by framing data-driven research through the lens of the right to health, my research advances understanding of the so-called 'normative elements' of PPPs, which have thus far been overshadowed by financial considerations.[892]

Furthermore, by framing the inequitable economic and political consequences of data-driven research through the lens of the right to health, my research demonstrates how international human rights law- as a robust legal framework enshrining universally-applicable moral standards-[893] can lend normative weight and legal authority to debates surrounding distributive data injustices and systemic power asymmetries. This implies the human rights framework may have an important role to play in policymaking efforts surrounding the governance and regulation of health data and data-driven research partnerships in and beyond the UK. My thesis thus contributes to efforts to centre civic values in data-driven research.[894]

[892] Ibid 12.
[893] Harris & Wyndham (n88).
[894] Sharon 'The Googlization of health research..' (n41); Sharon 'When digital health meets digital capitalism...' (n41).

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